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**Who should come into existence? An investigation of the ethical questions raised by new reproductive technologies and procreative decisions**

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*Awarding institution:*  
King's College London

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# WHO SHOULD COME INTO EXISTENCE?

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AN INVESTIGATION OF THE ETHICAL  
QUESTIONS RAISED BY NEW  
REPRODUCTIVE TECHNOLOGIES AND  
PROCREATIVE DECISIONS

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Submitted for the degree of Doctor of Philosophy

Department of Global Health & Social Medicine

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*Two dangers can be avoided if this idea of noncomprehensive systematization is kept in mind. One is the danger of romantic defeatism, which abandons rational theory because it inevitably leaves many problems unsolved. The other is the danger of exclusionary overrationalization, which bars as irrelevant or empty all considerations that cannot be brought within the scope of a general system admitting explicitly defensible conclusions. This yields skewed results by counting only measurable or otherwise precisely describable factors, even when others are in fact relevant.*

*The alternative is to recognize that the legitimate grounds of decision are extremely various and understood to different degrees. This has both theoretical and practical implications.*

*(Nagel 1979: 137)*

# ACKNOWLEDGEMENTS

For three years, I read people's experiences of working on a PhD. Personal accounts of these experiences are filled with horror stories about mental health breakdowns, drop outs, and financial and existential crises. This meta-research on doing a PhD while doing a PhD allowed me to appreciate how tremendously lucky I am and have been. I have been blessed with a team of great mentors, amazing friends and incredible students. I have received love and support beyond imagination. For all this, and for the difference it has made to my experience, I will be forever grateful.

My thanks go first and foremost to my supervisors, Silvia Camporesi and Barbara Prainsack. I have profited immensely from their invaluable feedback, advice and unwavering support. They have been with me every step of the way and caught me whenever I was about to fall. I have benefitted from (sometimes exploited) Silvia's work ethic, extraordinary commitment to the people she cares about, scholarly insights and friendship. Barbara has taught me the precious personal and professional lesson that rigorous scholarship can go hand in hand with grace, respect for and support of junior colleagues. For this and much more, I am eternally indebted to these two wonder-women.

That John Harris moved back to London was akin to a Kuhnian paradigm shift for me. John welcomed me as an unofficial PhD student and has mentored me tirelessly since. The time spent drinking wine and discussing philosophy has left an indelible mark on my thinking and writing.

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A close read of my work reveals a name that gets acknowledged numerous times. My friend and colleague Lorenzo Del Savio has read and commented on every sentence I have written; is responsible for many of my epiphanies (the good, the bad and the ugly) and has shaped my thinking more than anyone else. I am glad he left London just in time for me to be able to claim at least a bit of intellectual property on my own work.

What seems to be a defining feature of doing a PhD, loneliness, did not play part in my experience. This is due to the extraordinary people I have encountered along the way. With them, I laughed off bad days, danced out insecurity and climbed plastic rocks to fight the demons. I am particularly grateful to an amazing group of GHSM PhD students (you know who you are), and to Rob Smith, Karin Jongsma, Giorgio Di Gessa, my cheerleader (and co-author) of choice César Palacios-González and my academic better-half Federica Lucivero (even if it is still unclear who is mentoring who in our academic duo).

Not all children are welcomed into the world and too few get to experience the pure and unconditional love that I had the blessing to receive from my parents. I am grateful beyond words for this love and for what they taught me in terms of work ethic, insatiable thirst for knowledge and openness to the world. I am walking in your footsteps; thank you for being by my side each step of the way.

Also, not everyone has a partner with a self-awarded PhD in work-life balance. Matthias Lossek is what made my PhD possible by stopping me from doing it obsessively. Knowing my pathological tendency towards over-working, he showed me of all the beauty that there is beyond the academy. I am more and more conscious that there is no better playing, hiking, travelling, partying or laughing partner to discover the world with.

Lastly, if I managed to brush off sad days, if I always had a person to confide in, laugh with and rely upon, it is because of my academic twin. Sitting next to him crunching carrots has been one of the most fun and enriching experiences of doing a PhD. This thesis would be dedicated to him, if he would not think it to be the lamest thing in the world. Cheers, James Fletcher.

# ABSTRACT

This PhD thesis investigates ethical, social, and political questions raised by new reproductive technologies. Within this study, debates on the ethics of new reproductive technologies and on how these should be regulated in democratic societies are approached as debates on the ethics of eugenics. Eugenics has a bad reputation due to its tainted history, and 20<sup>th</sup> century eugenic policies and practices are often referenced to condemn new technologies. This study seeks to go beyond a negative understanding of eugenics to approach debates on the ethics of new reproductive technologies in terms of considerations of who should come into existence, and on how to distribute the burdens and benefits of such decisions.

This study consists of four parts. In the first part, I analyse and reflect on debates on the ethics of new reproductive technologies and show how these are characterised by moral disagreement and frequent references to 20<sup>th</sup> century eugenics. In the second part, I turn to ethical questions pertaining to new reproductive technologies more specifically. I discuss the ethical standing and implications of satisfying the preference to have genetically related children in connection with two technologies: genome editing and mitochondrial replacement techniques. In the third part, I discuss questions related to the governance of these technologies considering the plurality of ethical views and beliefs held by authors participating in these debates and members of the public. In the final part, I move from individual reproductive decisions and preferences to the far-reaching and cumulative effects of these decisions on third parties. I assess the strengths and weaknesses of the individual-centred framework that underpins reproductive freedom and of alternative frameworks that seek to account for the broader effects of procreative decisions.

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# ABBREVIATIONS

ANT	Altered nuclear transfer
ARTs	Assisted reproductive technologies
Cas9	CRISPR-associated protein 9
CRISPR	Clustered regularly interspaced short palindromic repeats
GDP	Gross domestic product
GHG	Greenhouse gas
GHSM	Department of Global Health and Social Medicine at King's College London
GRO	Genetic-relatedness objection
GRO-c	Genetic-relatedness objection: Consequentialist concerns
GRO-d	Genetic-relatedness objection: Deontological concerns
HFEA	Human Fertilisation and Embryology Authority

IVF	In vitro fertilisation
mtDNA	Mitochondrial DNA
MRTs	Mitochondrial replacement techniques
MST	Mitochondrial spindle transfer
nDNA	Nuclear DNA
PGD	Preimplantation genetic diagnosis
PND	Prenatal diagnosis
PNT	Pronuclear DNA transfer
STS	Science and technologies studies
U.K.	United Kingdom
U.S.	United States

# PREFACE

When I started this PhD project, twin souls were living inside me. I was the moral philosopher, proud to be one of only two women in my moral and political philosophy master's programme. I had been in love with philosophy since my first encounter with it in high school: finding consolation, challenge, and immense satisfaction from the questions it raised. I was also someone with a deep interest in applied ethics and bioethics. My philosophy soul and my bioethics soul got on well. My philosophical knowledge and skills, acquired after reading and studying philosophy for five years and spending an almost equal amount of time at the pub with friends discussing philosophical questions (can identity persist over time?); ethical dilemmas (should one be held equally responsible for drunk driving if nothing happens and if a bystander is killed?); and political problems (should there be conditions for registering to vote?<sup>1</sup>), seemed to be very useful for conducting research in bioethics. After all, I had always admired those in bioethics who combined sharp reflections and knowledge about the technologies, practices, and dilemmas at hand with philosophical skills, theories, and sound philosophical arguments. In short, I was a happy moral philosopher 'doing' applied ethics and bioethics. Then, I joined the Department of Global Health & Social Medicine (GHSM) at King's College London.

I had a bigger culture shock than when I first landed in Jakarta the summer before starting my PhD. It was a similar experience, though: very few colleagues spoke my language (the language of moral and political philosophy); very few of them seemed to think the way I did or were interested in the questions that kept me up at night, and many of them found it really amusing (in the best case) or thought it completely misguided (in the worst) that what interested me were the normative implications of what we discussed. I felt alien. I sometimes felt that the respect for my work and for

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<sup>1</sup> As is shown in the third part of this thesis, I stopped being so democracy-sceptic. The self-indulgence on the question of democratic governance was largely due to youth, love for Plato's *Republic* and Berlusconi repeatedly winning general elections.

my ideas that should be encouraged in multidisciplinary environments was lacking. At other times I was smug about the superiority of my own background, feeling like the 21<sup>st</sup> century heir of Diogenes. Luckily, smugness goes away with time. It also dissipates thanks to exposure to new ideas, ways of thinking, books, articles, and other sources that I would have never been exposed to if I had lingered, comfortably numb, in my cave. Discussions about social inequalities, mental health, ageing, and ‘genetisation’ in the meeting room of the fourth floor of the East Wing of the Strand Campus replaced my philosophical disquisitions. After countless lunch breaks, Foucault had almost replaced Plato and critical thinking had almost taken over from moral philosophy. Or more precisely: philosophy was forced to make space for all these new inputs and, believe me, at first it did not take this intrusion well. All the discussions I had, works I read, and lectures and talks I attended contributed to the emergence of a new tiny soul, the most alien to me and the one that was and is still in perpetual struggle against the two happily cohabiting souls described above.

As a result, this thesis is a hybrid. It combines normative and philosophical reflections *on* new reproductive technologies with reflections on bioethics as a field of inquiry and on debates *about* new reproductive technologies. It combines *doing* bioethics with *reflecting on* bioethics. And this is not all. I started this project concerned about people’s (reproductive) rights: not in the legal, but the deeper sense of this word. What interested and concerned me were people’s *moral* rights. Women with fertility issues, homosexual couples, single people, older women, and couples with a history of genetic conditions were all categories of people whose moral right to reproduce was curtailed. Sometimes these restrictions came from the state, in other instances from the Catholic Church (I am Italian, after all) and its reactionary beliefs, while at other times the responsibility lay with those who within the debate on the ethics of human enhancement came to be labelled ‘bioconservatives’. These were the enemies of these people, and as a result *my* enemies.

Conducting research in the U.K., a country with a much more liberal outlook to assisted reproduction than Italy, and in a multidisciplinary department like GHSM taught me a lesson: namely that what I have just described is possibly the narrowest approach to take to reflect on these issues. By this, I mean that questions related to

assisted reproduction and procreation more generally are much more complicated than I had thought. They are not only about moral rights. My supposed enemies are not the only (nor probably the biggest) obstacles to building a just society, and the people whose rights I was and to a certain extent am still so concerned with are likely to be those at the ‘top one per cent’ (Chomsky 2012). This means on the one hand that they are privileged people whose reproductive rights may well be curtailed in significant and unjust ways, but they are probably neither the most discriminated against nor the ones suffering the most; on the other, that the obstacles to a more just society from the perspective of reproductive rights needs to be built on something more than attacking conservatives and the Catholic Church. The take-home message of these three years and of the emergence of my new tiny critical soul was that the whole picture is much more complicated than it had seemed. I am talking Kandinsky’s *Composition VII*-complicated, while initially I thought of it as a Delacroixian *Liberty Leading the People* sort of complexity.



Eugène Delacroix, *Liberty Leading the People* (1830)



Wassily Kandinsky, *Composition VII* (1913)

This PhD thesis is hence the result of three (philosophy, bioethics, and social sciences) souls battling each other, challenging each other and by doing so, I hope, enriching the depth and quality of the outcomes. It is, as David Pizarro (2016) once put it (unfortunately not about my work), “the sneaky manifesto of a moral pluralist who believes that ethics are fundamentally messy” (Pizarro 2016: XIII). If it feels a

bit schizophrenic at times, or even just not harmoniously consistent, well, I blame you, GHSM.

However, as Thomas Nagel once (as so often) beautifully put it:

My own philosophical sympathies and antipathies are easily stated. I believe one should trust problems over solutions, intuition over arguments, and pluralistic discord over systematic harmony. Simplicity and elegance are never reasons to think that a philosophical theory is true: on the contrary, they are usually grounds for thinking it false. (Nagel 1979: X)

What will be the result of these considerations on people's reproductive rights and on bioethics scholarship? My hope is that they will contribute to debates on the ethics of new reproductive technologies by enriching them with data and sources testifying to the complexities of the social realities in which these technologies are debated, developed, implemented, and regulated. In my view, however, contributing to a field of inquiry should be just one of the many aims of academic endeavours. The aim of improving people's lives and, as John Harris (2016a) said, to "lighten the burden of human existence" (Harris 2016a: 16) is what needs to guide academic research and praxis<sup>2</sup>. This is easier said than done, but, in my view, debates on the ethics of new reproductive technologies are first steps towards developing and regulating technologies that can tackle obstacles to the satisfaction of people's procreative projects. The subject matter of this PhD thesis, namely an investigation of the ethical questions raised by these technologies and by procreative decisions, is then aimed at providing a way to deal with such obstacles.

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<sup>2</sup> An interesting way to articulate these aims is Jonathan Glover's distinction between *writing about* ethics and *practicing* ethics. Glover spoke about this in a personal communication.



# INTRODUCTION

This PhD thesis brings together sources from numerous academic disciplines. This is reflected in the body of this thesis and in its separation into different papers, which I describe briefly in this introduction together with the thesis' leading thread, aims, methodology, sources, and scope.

This thesis is fundamentally about eugenics<sup>3</sup>, but with some caveats. 'Eugenics' is synonymous with inhumane ideologies and despicable practices carried out during the 20<sup>th</sup> century<sup>4</sup>. It is identified with genocide; forced sterilisation; infanticide; discrimination against disabled people, minorities and women, and the institutionalisation and segregation of vulnerable subjects. Despite these associations, eugenics does not have entirely pejorative connotations. It permeates history and geography, defying simplistic explanations, clear depictions, and straightforward condemnations. While the knowledge of inhumane and despicable practices associated with it is widespread, eugenics encompassed a multiplicity of conflicting ideologies and heterogenic practices (Lombardo 2018; Meloni 2016; Paul 1984, 1998). The complexity of the past is often overlooked within accounts of authors participating in debates on the ethics of new reproductive technologies (Bashford 2010). Their appraisals of the morally troubling and acceptable features of 20<sup>th</sup> century eugenics vary and often result in conflicting assessments of the morality of the present. The multifaceted nature of 20<sup>th</sup> century eugenics (Meloni 2016; Paul 1998) and concomitant ethical assessments of this history make eugenics a 'handle-with-care' tool in debates on the ethics of new reproductive technologies. Intrinsically, a comparison between past and present that is not mindful of the

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<sup>3</sup> For now, I follow Stephen Wilkinson's (2010) approach and rely on a 'working definition' of eugenics, which I define as 'the attempt to influence the genetic endowment of future generations'. I return to the question of the definition of eugenics in the first part of this thesis, where I discuss the multiple definitions of the word 'eugenics' and the implications for debates on the ethics of new reproductive technologies of using a certain definition.

<sup>4</sup> While for some eugenics is synonymous with *past* inhumane and despicable practices, for others it is not, as it were, 'a thing of the past', but alive and well thanks to contemporary reproductive technologies and practices. I discuss these two views in Paper 1 (Cavaliere 2018d).

complexities of the history of eugenics and of new reproductive technologies risks being epistemically and normatively problematic. It risks flattening the ethical questions raised by new reproductive technologies into binary thinking of ‘analogous to eugenics’ versus ‘disanalogous to eugenics’. This risks making only partial ethical assessments of new reproductive technologies and thereby failing to contribute in meaningful ways to users, policy-makers, and to bringing forward ethical debates.

Eugenics is not only associated with inhumane and despicable practices but also with adverse emotional reactions caused by the memory of these practices and of the policies enacted in its name (Wilkinson 2008). Authors discussing the ethics of new reproductive technologies have argued against employing the word ‘eugenics’ within these debates (Camporesi 2014; Wilkinson 2008), and against its use as a cautionary tale to warn against potential negative externalities of such technologies (Paul 1992). According to this understanding, eugenics casts a shadow on debates on new reproductive technologies, and its emotive power risks circumventing “people’s rational-critical faculties” (Wilkinson 2008: 471). Indeed, eugenics has been depicted in pejorative terms as a shadow, a ghost, and a conversation-stopper. Despite these negative depictions, one of my arguments throughout this thesis is that debates on the ethics of new reproductive technologies, and of procreative decisions and procreation more generally are debates about *what kind of people should come into existence*<sup>5</sup>, and about how to balance the burdens and benefits of such decisions. These debates are, ergo, about the ethics of eugenics. They are about what the prefix ‘eu’ (good) in eugenics amounts to; what are and are not favourable traits; and what weight, if any, should be granted to people’s preferences in procreative matters. They are also about intentionally and technically intervening in the type and number of people who will inhabit our planet, and about how to distribute the burdens and benefits of these decisions.

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<sup>5</sup> This deliberately echoes Jonathan Glover’s (1984) question “What sort of people should there be?” (Glover 1984). This question is the title of Glover’s book on “the future of humankind” and “the ethics of genetic choices” (these descriptions are from Glover’s website, at: <http://www.jonathanglover.co.uk/books/what-sort-of-people-should-there-be> (last accessed: 11 July 2018)).

In addition, another overarching argument of this thesis is that 20<sup>th</sup> century eugenics does not only cast shadows but can also shed light on some of the complexities of the present. In other words, reflecting on the meanings of the word ‘eugenics’, and on the implications of its use in debates on the ethics of new reproductive technologies and on procreative decisions allows us to uncover certain tensions and complexities in these debates, and of the technologies and practices at their heart. It allows us to see how the complex negotiation of conflicting values and tensions “between social good and individual liberties” (Buchanan et al. 2001: 30) that characterised eugenics is still part of today’s discourses and negotiations of values (Löwy 2015). To give an example, the tensions which Allen Buchanan and his co-authors (2001) identify are alive and well in contemporary discourses and rationales of whether to offer prenatal screening (Löwy 2015: 199). Within these discourses and rationales co-exist “incommensurable moral economies” (Löwy 2015: 199), namely tensions between individual-centred measures and practices on the one hand and public health concerns and population-wide measures and practices on the other<sup>6</sup>.

In the following sections I present the aims, the questions, the methodology that guided the research that led to this thesis, and the sources that informed it. The main contribution to the bioethics literature on the ethics of new reproductive technologies of this thesis lies in its multidisciplinary outlook, and on its bringing together a multiplicity of sources and reflections from authors belonging to different disciplines. In addition, reflecting on ethical questions raised by new reproductive technologies in terms of eugenics (as I have just discussed, and as I discuss further in Parts I and IV) allows for the uncovering and unpacking of existing tensions and pluralistic understandings of the ‘good’ within debates on the ethics of new reproductive technologies and procreative decisions.

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<sup>6</sup> Ilana Löwy (2015) argues that “the generalization of PND and its transformation into screening technology was strongly affected by two events: the recognition of the right of women at high risk of giving birth to severely handicapped children to terminate their pregnancies; and the aspiration of reducing the prevalence of a specific congenital condition, Down’s syndrome” (Löwy 2015: 199). According to this understanding, the tension between focusing on the individual and on the population is part of 20<sup>th</sup> century eugenics that survives in contemporary reproductive technologies.

## 1 Aims, Questions, Methodology, and Sources

The questions discussed in this study are informed by my training and work in both philosophy and bioethics, and are also influenced by my knowledge of social sciences. The heterogeneity of my background is reflected in the variation between meta-reflections on debates on the ethics of new reproductive technologies and procreative decisions, and reflections on the ethics of new reproductive technologies and procreative decisions. It is also reflected in the aims of this project, its guiding questions, and the methodology employed to address these questions, which are discussed in the following sections.

This project has two overarching aims; both concern questions of who should come into existence, and of how to balance the burdens and benefits of these decisions. As I discuss in the methodology section, in the past two decades bioethics has been subjected to several critiques which have given rise to a series of related proposals to change this field of inquiry<sup>7</sup>. This project takes as a point of departure these critiques and subsequent proposals to make bioethics more grounded in ‘the real world’, but it seeks to go beyond them. The first aim of this project is hence methodologically oriented as this thesis endeavours to provide an example of how debates on new reproductive technologies can be enriched by an attention to the complexities of social realities and by being more inclusive in terms of disciplinary sources. To achieve this, I use debates on who should come into existence as case studies and examples<sup>8</sup>: I observe, analyse, and evaluate them to work towards this aim.

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<sup>7</sup> Here, I follow Daniel Sulmasy and Jeremy Sugarman’s (2010) definition of discipline as “a department of learning or knowledge, a community of scholars who share common assumptions about training, modes of inquiry, the kind of knowledge that is sought, and the boundaries of the subject matter proper to the discipline” (Sulmasy & Sugarman 2010: 5); and field of inquiry defined as “a subject matter or set of phenomena or questions addressed by a scholar of scholars” (Sulmasy & Sugarman 2010: 5). Considering the diversity in terms of methodology, and types of knowledge and training within bioethics, I am inclined to describe it in terms of a field of inquiry that is of “great interest to many disciplines rather than a discipline in its own right” (Sulmasy & Sugarman 2010: 5).

<sup>8</sup> While the conclusions and recommendations for future debates concern debates on the ethics of eugenics, these conclusions and recommendations could be trialled in other debates in bioethics.

## Introduction

The second aim of this project concerns more specifically the question of who should come into existence, and of how to balance the burdens and benefits of decisions made in light of it. It seeks to provide an analysis and evaluation of these questions and to this effect is subdivided into three specific goals. The first goal is to provide arguments and to produce ethical assessments which contribute to making new reproductive technologies more widely accessible to people who suffer from infertility due to medical and/or social reasons; to non-heterosexual couples, and to people who carry inheritable genetic conditions who wish to pursue parenthood projects. The second goal is to provide arguments for implementing new reproductive technologies and for organising procreation in ways which fairly distribute their burdens and benefits. The third goal is to provide arguments for making these technologies implemented in ways which respect the plurality of values and world-views concerning them; to ethically balance the burdens and benefits of satisfying people's procreative preferences, and to take into consideration the wide-reaching and cumulative effects of procreative decisions.

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Several questions guided the research that led to this thesis. The first set of questions pertains to debates on the ethics of new reproductive technologies and procreative decisions.

- What is the role of the reference to eugenics within debates on the ethics of new reproductive technologies?
- What are the argumentative strategies pursued by authors participating in these debates considering the moral disagreement that surrounds these technologies?
- Which ethical frameworks other than the individual-centred framework of reproductive freedom can be employed to discuss the ethics of procreative decisions?

A second set of questions relates more specifically to the ethics of new reproductive technologies and procreative decisions.

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- How should the preference for genetically related children be weighed against other considerations (such as those pertaining to resource allocation and negative externalities of new reproductive technologies)?
- What limits if any should be imposed on the satisfaction of people's interests and preferences in procreative matters?

A third set of questions pertains to the governance of new reproductive technologies.

- How much weight should competing values and world-views on new reproductive technologies be granted in practice?
- What criteria can assist in attributing priority to values and world-views in practice?
- How can a respect for values and world-views be reflected in regulatory strategies?

Each part of this thesis attempts to address one or more of these questions.

### 1.1 Methodology: Critical Bioethics and Beyond

Methodology is not an easy matter for philosophers. One of the recurrent jokes about my PhD project within my social sciences department was that I, contrary to most of my colleagues, 'did not collect data'. As a result, or this is how the friendly teasing went, I did not have a methodology: I could not have the standard methods chapter in my thesis describing how I collected original data; which theory I used to analyse it; which software aided me in the coding; and how I then wrote-up my findings chapters. This idea of an un-empirically-informed analysis of the subject is not limited to friendly teasing among colleagues, it is also an inside joke among philosophers.

In addition to philosophers and my colleagues, others criticise the effects of the philosophical foundations of bioethics<sup>9</sup> and the lack of empirical grounding of this

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<sup>9</sup> For a critique of foundationalism in bioethics, see also Susan Sherwin (1999) and (2008).

field of inquiry. The so-called “social science critique of bioethics”<sup>10</sup> (Hedgecoe 2004: 121) stems from the idea that bioethics, due to its philosophical foundations, is overly formal, deductive, and rational (Bosk 2000; Fox 1999); that ethical analyses transcend people, time, and place (Bosk 2000); and that the complexities of social and cultural factors are sacrificed in the name of “universal ethical principles” (Fox 1999: 9). In other words, the social science critique of bioethics charges research in this field of inquiry with a lack of attention to empirical data: its meanings, implications, and value. Importantly, following these authors, this flaw can be traced to bioethics’ foundation in philosophy. This cluster of critiques inspired Adam Hedgecoe’s (2004) idea of “critical bioethics” (Hedgecoe 2004: 120), which, as the author points out, seeks to go “beyond the social science critique” of bioethics (Hedgecoe 2004: 120).

Despite the teasing, the social science critique of bioethics and this project being indeed informed by desk-based philosophical research, there is a methodology behind this study and a multiplicity of sources inform it. My methodology is inspired by Hedgecoe’s (2004) and others’ (Árnason 2015; Ives & Dunn 2010; Twine 2005) calls for bioethics to become critical bioethics. I firstly present and discuss these authors’ proposals and show how my overall methodology both builds on and

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<sup>10</sup> For instances of authors putting forward this critique, see Renée C. Fox (1999) and Charles L. Bosk (2000). Adam Hedgecoe (2004) aptly summarises the main tenet of the social science critique as follows: “bioethics, founded on philosophy, gives a dominant role to idealised, rational thought; it tends to position individuals as the sole judge in ethical decision-making, in that it relegates social and cultural aspects to the status of at best, curios, and worst irrelevancies; the applied ethics model assumes that social reality cleaves down neat philosophical lines, with theoretical categories matching those in social reality: i.e. that what a philosopher says is the doctor-patient relationship actually represents the relationship between doctors and their patients in all settings. Consequently, bioethics does not have the right tools to resolve substantive moral problems, external to these categories themselves” (Hedgecoe 2004: 130). On this issue, see also Alan Cribb and John Owens (2017) on “sociological bioethics” and “philosophical bioethics” (Cribb & Owens 2017: 103-104). An appraisal of the social science critique of bioethics is beyond the scope of this project. What I instead discuss in the following section is Hedgecoe’s (2004) and others’ (Árnason 2015; Ives & Dunn 2010; Twine 2005) proposals to move towards ‘critical bioethics’. I discuss this proposal instead of the specifics of the social science critique of bioethics, as I believe that it is more up-to-date with respect to the sources that it appraises and true to current bioethical debates more generally. It is not solely critical of bioethics, but it attempts to provide some recommendations on how bioethics can be brought forward and it captures several elements of the social science critique of bioethics whilst attempting to offer constructive suggestions rather than a mere assessment of the discipline (on this issue, see also De Vries 2004).

departs from these proposals. I then move to the sources that I relied upon for this project and that I believe need to be integrated into bioethics more generally.

Hedgecoe is arguably the father of critical bioethics, as he outlined and explained for the first time which conditions need to be met for bioethics to be ‘critical’. The expression ‘critical bioethics’, however, comes from Lisa Parker (1995), who coined it to describe her approach which “*critically interrogate[s] the normative and conceptual schemes* within which ethical considerations about such [breast cancer genetic] screening protocols are framed” ([emphasis added] Parker 1995: 313).

What critical bioethics more generally stands for is the need to take empirically informed approaches to discussions of bioethical questions, technologies, and practices; for the critical self-reflection that authors conducting research in bioethics should exercise with respect to their own assessments, judgments, and to the decisions they support, as well as for favouring breadth and depth rather than only analytic clarity and consistency within ethical assessments (Árnason 2015; Hedgecoe 2004; Ives & Dunn 2010; Twine 2005). More specifically, to become ‘critical’, bioethics needs to be empirically rooted, theory challenging, reflexive, and politely sceptical (Hedgecoe 2004). Critical bioethics is “empirically rooted” and “bottom up” in that it uses as “first port of call” empirical data collected by social scientists rather than “standard bioethics debates” (Hedgecoe 2004: 136). It needs to avoid blind reliance on moral theories as the principal source of action-guiding ideas, especially when the preferred moral theory does not fit the complexities and structures of the social world in which it seeks to intervene<sup>11</sup>. It should also not take

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<sup>11</sup> This reliance on theories in ‘applied philosophy’ is also criticised from within (i.e. from philosophers). An instance of this is in Jonathan Wolff (2018). There, Wolff is concerned with how moral and political philosophy can be used in the context of public policy and with the role of philosophers in advising on these policies. He argues that those who seek to apply theories in political and moral philosophy to public policy face a number of difficulties: dogmatism, under-determination, implausibility of recommendations, theory of the second best, blindspots, and conceptual inadequacy (Wolff 2018). An analysis of each of these elements is beyond the scope of this thesis, but many of them echo social scientists’ critiques of bioethics. Another instance of criticism in this direction (again ‘from within’) is in Allen Buchanan (2002a). Buchanan explains that “applied ethicists tend to focus exclusively on two tasks: identifying valid moral principles and constructing arguments in support of them. This constructive enterprise is often preceded by the critique of rival principles, either by showing that the rival principles are incompatible with widely shared considered judgments (moral intuitions) or by exposing the unsoundness of the arguments offered in support of the principles” (Buchanan 2002: 128). He goes on to criticise this approach, and to show that it can lead to



traditional moral theories' practical utility for granted and blindly apply them to specific dilemmas and cases. Instead, it needs to use empirical data and research in the social science field to challenge these theories and to test their practical utility. Critical bioethics also requires self-reflection on the cultural, political, and social realities which shape bioethicists' reflections and that play a role in the formation of their moral judgements. Building on Hedgecoe (2004), Jonathan Ives and Michael Dunn (2010) emphasise the social- and cultural-embedded nature of bioethics<sup>12</sup>. They argue that bioethicists need to explicitly address and reflect on their biases, assumptions, motivations, conflicts of interests, and other aspects which may influence their moral assessments of certain technologies or practices<sup>13</sup>. In other words, critical bioethics demands similar practices to those performed by social scientists and emphasises that there is a need to conduct "a critical interrogation of the relationship between the researcher, the world she is studying and her experience and awareness of that world" (Ives & Dunn 2010: 261).

Lastly, critical bioethics should challenge epistemic scientism (Mayes et al. 2015) and be politely sceptical: ready to challenge and be critical of claims made by other bioethicists, scientists, and healthcare professionals, especially about the reliability and promises of scientific research and findings, and thereby emulating an attitude typical of the critical traditions of the social and political sciences.

### 1.1.1 Beyond Critical Bioethics

My methodology seeks to incorporate these features and strives to be empirically rooted, theory challenging, reflexive, and politely sceptical, *with some caveats*. My research, and the methodology that underpins it, is empirically informed (rather than rooted, a difference that I qualify further on in this section) and context-aware. It

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epistemologically false and morally problematic beliefs if it is not paired with what he refers to as "social moral epistemology", namely the "study of the social practices and institutions that promote (or impede) the formation, preservation, and transmission of true beliefs so far as true beliefs facilitate right action or reduce the incidence of wrong action" (Buchanan 2002a: 126).

<sup>12</sup> For a discussion and problematisation of the communitarian self and of human beings as socially embedded, see Michael Parker (2005a).

<sup>13</sup> See also Parker (2007) on reflectivity and bioethics (Parker 2007: 190).

pays attention to the social character of bioethics and its unfolding in a certain period of time and geographical space within certain political, cultural, and social contexts. It recognises, therefore, that moral, social, cultural, and political values contribute to deciding which questions are addressed, which technologies are developed, and which lines of inquiry are considered worth pursuing (Kitcher 2001, Ch. 7). It draws upon empirical data that can, on the one hand, shed light on how such values shape moral beliefs about new reproductive technologies and bioethicists' ethical assessments of such technologies. On the other, they can show how such technologies shape or, borrowing from Sheila Jasanoff (2004), co-produce these values (Jasanoff 2004). From this perspective, the difference between empirically informed and empirically rooted is both a matter of degree and nature<sup>14</sup>. It is a matter of degree in that my research contains elements of a bottom-up approach (what I believe an 'informed' approach entails) rather than being *entirely* bottom-up (what a 'rooted' approach would entail). It is also different in nature as it includes *both* elements of bottom-up as well as top-down approaches, and as it dynamically moves between these extremes<sup>15</sup>.

What my methodology entails is a sort of reflective equilibrium<sup>16</sup> between empirical data, reflections of authors with different disciplinary backgrounds (which I discuss below), and moral theories. 'Reflective equilibrium' describes both a moment as well

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<sup>14</sup> Here, it is worth noting a distinction that Eve Garrard and Stephen Wilkinson (2005) draw between data that are 'part of the ethical debate' and 'relevant' to such debate. According to the authors, being part of the ethical debate entails that empirical data determine the rightness and wrongness of a given situation or a set of different courses of action, while being relevant to a certain debate entails that data play a more ancillary role to such debate. Following this distinction, an empirically informed approach would take empirical data as relevant to rather than part of the debate.

<sup>15</sup> My methodology does not consist in systematising and generalising empirical findings. It also does not consist in what is sometimes identified with applied ethics, namely the process of: formulating (or selecting) the 'right' moral theory, showing how it could resolve the moral dilemma that is under consideration, and developing arguments to show the utility of such theory in real-life dilemmas and cases. It is this kind of approach that is criticised by Hedgecoe (2004), but also by Wolff (2011) in the context of the role of philosophers in public policy. Such an approach is precisely what social scientists who criticise bioethics would find wanting, overly deductive and abstracted from the cultural, political, and social contexts where the dilemma arises.

<sup>16</sup> The process of reflective equilibrium was first introduced by Nelson Goodman (1955) with respect to the justification of rules of inference in inductive and deductive logic. It was John Rawls (1971), however, who brought this concept to moral and political philosophy and who made it well-known by using it both to construct and to justify his theory of justice (see also Scanlon 2002).

as a process in moral reasoning whereby one's considered moral judgements about specific actions, institutions or policies form a coherent whole with a set of general moral principles which serve to ground these judgements. Within the process of reflective equilibrium, revision cuts two ways: the principles can be revised or abandoned altogether if they do not match one's stable and reliable considered moral judgement about the case at hand, and the considered moral judgement has to be revised or dismissed altogether if it is at odds with the relevant set of principles proven to be applicable to a wide range of alternative cases. My methodology implies *a sort of* reflective equilibrium, in that additional elements are introduced to this balancing process. As Ghislaine J.M.W. van Thiel and Johannes J.M. van Delden (2017) nicely summarise, the beliefs relevant to reflective equilibrium are "(i) considered moral judgements or moral intuitions (ii) morally relevant facts (iii) moral principles (iv) background theories or ideals" (van Thiel & van Delden 2017: 160).

What instead inspires my research and grounds my methodology is a reflective equilibrium whose elements include: 1) empirical data from different disciplines (which would be part of the morally relevant facts described by van Thiel & van Delden [2017]) that can challenge and question the reliability of our considered moral judgements and of the intuitions that underpin them; 2) theories and ideals which do not only draw on moral philosophy but on a wealth of methodological and conceptual sources. These theories and arguments are hence revised in light of the empirical findings I draw upon and, in turn, the interpretation of such empirical findings is revised in light of a new theoretical understanding enriched by the different disciplinary sources I bring in.

As a result, my research (and the methodology that underpins it) is also theory challenging: despite having my own sympathies and beliefs in terms of a preferred moral theory (and preferred meta-ethical theory), my research strives to avoid dogmatic applications of abstract theories. It also strives to avoid what Thomas Nagel (1979) describes as the "danger of exclusionary overrationalization"<sup>17</sup>, which

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<sup>17</sup> Nagel (1979) warns against two dangers: the danger described in this sentence and the danger of "romantic defeatism, which abandons rational theory because it inevitably leaves many problems unsolved" (Nagel 1979: 137).

“bars as irrelevant or empty all considerations that cannot be brought within the scope of a general system admitting explicitly defensible conclusions” and which may yield “skewed results by counting only measurable or otherwise precisely describable factors, even when others are in fact relevant” (Nagel 1979: 137). Sacrificing complexities, nuances, and the messiness which inevitably characterises moral and social realities in the name of elegance and of a universally applicable moral theory needs to be avoided. An elegant theory that does not match these complexities and nuances will be limited in terms of both analytical validity and practical utility. It will be limited in its capacity to properly describe, understand, and evaluate social and moral realities, and it may end up prescribing rules and duties which are partial at best and damaging at worst. At the same time, even granting that critics of bioethics faithfully depict it as overly rational, deductive, and rooted in analytic philosophy, as well as blindly applying moral theories to social realities<sup>18</sup>, for bioethics to remain a normative enterprise<sup>19</sup> then moral theories are necessary (Garrard & Wilkinson 2003). Theories function as both analytical and normative tools for reasoning in bioethics. What these moral theories need is to be aided by empirical observations and data which can challenge ethical assessments of technologies and practices that risk yielding the skewed results mentioned above.

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<sup>18</sup> I am (politely) sceptical with respect to the social science critique of bioethics and to some of the evidence presented in support of its portrayal of bioethics. First of all, it is unclear, and largely an empirical question, as to whether bioethics really is as deductive, overly rational, and blindly applied as they state. While it is true that bioethics has its origins in North America and in the U.K. where analytic traditions are perhaps more prominent than in Continental and critical traditions, bioethics is a rather heterogenic field. In recent years, the influence of hermeneutic, phenomenological, and other Continental traditions in bioethics has been growing, and – with respect to debates on the ethics of genetics and new reproductive technologies – the work of authors such as Jürgen Habermas (2003); Catherine Mills (2011); Barbara Prainsack (2017); Barbara Prainsack and Alena Buyx (2011); and Jackie Leach Scully (2008) are just a few examples of this influence. Similarly, empirical bioethics is a growing methodology within bioethics, as is testified by the growing number of papers, research projects, and debates around this issue. See, for instance, Jonathan Ives, Michael Dunn and Alan Cribb (2017); Cribb and Owens (2017); John McMillan (2017); Mark Sheehan (2017); and others in Ives, Dunn and Cribb (Eds.) (2017). In light of this, I believe that one could say that the burden of proof should fall on those who criticise bioethics to provide evidence for their claims that is not cherry-picked, and that does not oversimplify and misrepresent bioethics scholarship.

<sup>19</sup> See also Cribb and Owens’ (2017) helpful discussion of prescriptive and descriptive methodological orientations (Cribb & Owens 2017: 110-113).

## Introduction

My methodology also contains elements of self-reflection on the nature of my assumptions and on the contextual elements contributing to their formation<sup>20</sup>. These concern the following observations: I am an Italian philosopher who was raised Catholic and then became agnostic; I was born and raised in the West, and I emigrated to the U.K.; I have worked closely not only with philosophers but also with social scientists and medical doctors; I have not fully decided which meta-ethical views I subscribe to; and I have a certain inclination to be a contrarian. As such, I strive to be as reflective as possible on how disciplinary backgrounds, experiences, contexts, and other elements influence my reasoning and might influence the reasoning of the authors who influence my work. For instance, I am aware of how my highly critical perspective on the interference of the Roman Catholic Church in the Italian governance of new reproductive technologies can be a source of negative bias towards religious positions in these debates. In addition, being a philosopher in a social sciences department has helped to widen the scope of my reflection, and to allow me to perceive the contribution that scholarship in this field can offer to bioethics. I am cognisant, though, of the issues with this integration and on different disciplines' assertions of superiority over others (see also Cribb & Owens 2017: 103-107). All these elements help me to be politely sceptical about claims made not only by bioethicists but also by scientists who develop new reproductive technologies and by policy-makers who seek to implement these in practice.

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In sum, the aim of this project is twofold. Its methodology-oriented aim is to provide an example of how debates on the ethics of new reproductive technologies can be enriched by attention to the complexities of the 'real world' and by being informed by different disciplinary sources. Its content-oriented aim is to analyse and evaluate claims on the ethics of these technologies in order to make these technologies more accessible and regulated in ways which take into account the aforementioned

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<sup>20</sup> In what follows, I shamelessly borrow both style and methodology (autoethnography) from Ives and Dunn (2010).

complexities. Both these aims concern debates on the ethics of eugenics, i.e. they concern the question of who should come into existence and how to balance the burdens and benefits of these decisions. The methodology employed builds on many elements of the critical bioethics endeavour. Despite this, it seeks to go beyond such endeavour. It seeks to be empirically informed, theory challenging, reflexive, and politely sceptical, and to bring together in a reflective equilibrium a variety of theories, data, and other sorts of sources to avoid the two dangers described above: “romantic defeatism” and “exclusionary overrationalization” (Nagel 1979: 137).

I now turn to the sources that are part of this reflective equilibrium.

### 1.2 Sources

In addition to the methodological observations just described, this research is informed by and builds on a variety of sources. In this section, I provide examples of sources which have informed my research on the ethics of eugenics and argue that they should be integrated into bioethics scholarship more generally.

#### 1.2.1 Social Sciences and History

The first set of sources to inform my research, as I mentioned above, is from the social sciences. Empirical data on the experience of prospective parents using preimplantation genetic diagnosis (PGD) (Franklin & Roberts 2006) and on women affected by mitochondrial disorders (Herbrand 2017; Herbrand & Dimond 2018) might not settle the question of whether PGD and mitochondrial replacement techniques (MRTs) are ethically acceptable technologies. Similarly, public attitudes concerning the extension of the 14-day statutory limit to conduct research on human embryos might not settle the question of whether the 14-day limit should be changed. Alone, these data and sources do not tell us whether these technologies and embryo research ought to be allowed or banned, or publicly or privately funded. What they can do is inform assessments concerning public policy decisions on the governance of new reproductive technologies. These data and sources are, following Eve Garrard and Stephen Wilkinson (2005), *relevant to* debates on the ethics of

PGD, MRTs, and embryo research. Integrating them into bioethics would allow for an ethical debate and for ethical assessments which are mindful of the tangible effects of technologies and practices on users, on other members of society, and of the less tangible effects on people's values and beliefs. It would allow for debates informed by the social and political context in which technologies and practices are developed and discussed, thereby avoiding assessments that over-generalise and dogmatically offer one-size-fits-all solutions.

Another set of sources to inform my research comes from the work of political scientists, historians, and science and technology studies (STS) scholars who challenge certain assumptions that underlie debates in bioethics. For instance, historians have questioned the dominant views on the solely coercive nature of 20<sup>th</sup> century eugenics, which permeate debates on the ethics of new reproductive technologies and of human enhancement. Accounts of historians, such as Alison Bashford (2010, 2014); Matthew Connelly (2008); Diane B. Paul (1992, 1998); Paul A. Lombardo (2011, 2018); and Daniel Kevles (1985), and STS scholars such as Maurizio Meloni (2016), help to shed light on the complexity of the history of eugenics. Their assessments also reveal the fallacy of equating 20<sup>th</sup> century eugenics with coercion and population-level interventions, and contemporary technologies and practices with freely-chosen and individual-level interventions (Bashford 2010; Meloni 2016; Paul 1992). Such an equation, as they show (and as I discuss further in Paper 1, Cavaliere 2018d), is neither supported by sound historical analysis nor, one could argue, by an adequate understanding of the complexities of the present.

The work of STS scholars such as Jasanoff (2011) and J. Benjamin Hurlbut (2017) bring to light how biases, values, incentives, power relationships, and other external influences can play a role in scholars' assessments of reproductive technologies and of their social and public value. In Hurlbut's (2017) account of the history of the debate on human embryo research in the U.S., he effectively shows that scientists occupied a privileged position in the debate due to their recognised epistemic authority to settle ontological questions of what the embryo *is*. Contrary to those of other participants in the debate, scientists' views were not subjected to similar critical scrutiny. They also became a sort of extra-political entity serving as a

foundation of the public debate over embryo research rather than as one of the many aspects of this debate (Hurlbut 2017). As I argue in a review of Hurlbut's *Experiments in democracy: Human embryo research and the politics of bioethics* (Cavaliere 2018b), bioethicists can learn more about their own role as active participants in the debate on embryo research from his account of this debate:

According to Hurlbut, we should keep in mind that science and democracy are mutually constituted human institutions. Hence, we are asked by the author to subject science to the very same tests of legitimacy that are usually performed to democracy. If we believe that democratic political authority is not naturally given and hence not unquestionable, by the very same token we should question science, its authority, and its power. (Cavaliere 2018b)

Another useful account for fostering critical and politely sceptical analyses, and for uncovering complexities of the subject matter of bioethics, is Barbara Prainsack's (2017) work on personalised medicine. Building on Peter E. Digeser (1992) and the work of Michel Foucault, Prainsack shows how the optimistic idea that medicine empowers patients through technologies is built on a simplistic account of power and of the "material capabilities that an actor has at her disposition and assume[s] that actors exercised their power rationally" (Prainsack 2017: 84). Instead, what the author proposes is a more nuanced account of power and of its several faces (Digeser 1992), which permeate the interplay of medicine and society. Such analyses (together with the work of Nikolas Rose, see Rose [2007] and Hurlbut, see Hurlbut [2015, 2017]) help bringing to the fore power relations which traditional dichotomies such as autonomy/paternalism, exploiting/liberating are too simplistic to account for. Lastly, the work of social scientists and feminist scholars such as Dorothy E. Roberts (1997), Catherine Mills (2011), and Michelle Murphy (2017); the work of those arguing for reproductive justice<sup>21</sup> (Ross 2006); and the work of those discussing stratified reproduction<sup>22</sup> (Colen 1995; Ginsburg & Rapp 1995; Mamo &

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<sup>21</sup> I return to reproductive justice in Part IV. This label describes a cluster of theories and activists' claims seeking to reconcile the work of reproductive rights activists and those concerned with social justice.

<sup>22</sup> The term 'stratified reproduction' was originally introduced by Shellee Colen (1995) to describe power relationships within reproduction whereby "some categories of people are empowered to



Alston-Stepnitz 2015) challenge dominant narratives on the value of reproductive freedom, and on its potential to redress past wrongs with state neutrality and non-interference in procreation.

### 1.2.2 Moral and Social Psychology

Studies in moral and social psychology on the formation of moral judgements are analytically and epistemologically helpful for understanding and challenging assumptions about the rationality of certain assessments versus others (Haidt 2012). They are also analytically and epistemologically useful for debates characterised by deep moral disagreement (Greene 2014; Haidt 2012). Integrating studies on moral judgements and on moral and political disagreement can enrich understandings of the causes of disagreement and foster the adoption of a self-reflective attitude in authors participating in normative debates. For instance, studies on framing effects, i.e. on how words' type and order, context and phrasing can influence people's decisions and judgements in a given situation (Lakoff 2004; Petrinovic & O'Neill 1996; Tversky & Kahneman 1981), are relevant to debates in bioethics. Framing effects can influence people's moral intuitions and moral assessments of a given situation, dilemma, or, I would argue, technology, depending on how it is described and presented. As I discuss in Paper I (Cavaliere 2018d), people's moral beliefs regarding specific reproductive technologies can be subjected to word-type framing effects. Thus, their beliefs about the technology depend on the way the technology is described and on which words are used to do so rather than on specific characteristics of the technology in question. Considering the literature on framing effects can not only increase awareness of one's own uses of language in bioethics debates but also foster self-reflection with respect to the sources of one's own moral beliefs concerning new reproductive technologies.

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nurture and reproduce while others are disempowered" and "arrangements by which some reproductive futures are valued while others are despised" (Ginsburg & Rapp, 1995: 3).

### 1.2.3 Moral Philosophy and Meta-Ethics

Moral philosophy and meta-ethics also inform my work and, I contend, need to be integrated into bioethics scholarship more generally. Moral philosophy, and especially the analytic tradition, influences my reasoning and how I structure my arguments on the ethics of new reproductive technologies and procreative decisions. As mentioned above, empirical data can provide information and analyses which are relevant for debates in bioethics. What it cannot do (alone) is settle the question of whether a certain reproductive technology should be implemented or not, whether its features are ethically permissible, what this entails, and so on. It is thanks to moral theories that technologies, actions, institutions, and their social and political implications can be ethically assessed. Moral theories need to be fed in with other information and sources to generate action-guiding principles and prescriptions (Garrard & Wilkinson 2003), but they are necessary in the exercise of balancing conflicting assessments, data, values, and beliefs. For example, moral theories can assist in the reflection on and assessment of the ethical challenges raised by new reproductive technologies such as MRTs. As argued above, data on users and usages of MRTs play an important role in making debates on the ethics of these technologies more mindful of the context in which they are developed, discussed, regulated, and implemented. Similarly, a discussion of the rightful limits that can be imposed on people's procreative preferences cannot be settled solely with the aid of empirical data. Bioethics is about how to act at the individual, social, and institutional level. It is about normative judgements and assessments. It is about the subject matter of moral theories.

Secondly, I contend that bioethics needs meta-ethics<sup>23</sup>. Within debates on new reproductive technologies and perhaps within bioethics debates more generally, authors tend to talk past each other and to focus on pointing out the fallacies and inconsistencies of each other's arguments in favour of or against new reproductive technologies<sup>24</sup>. Sometimes, however, disagreement not only arises from conflicting

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<sup>23</sup> I am not alone in contending this; see, for instance, Garrard & Wilkinson (2003).

<sup>24</sup> See Matti Häyry (2010) on this issue within the context of the debate on human enhancement.

moral beliefs but also from conflicting (and often unacknowledged) meta-ethical commitments. A case in point (further discussed in Paper 5, Cavaliere 2017) is the early days of the debate on whether embryo research should be allowed. The chair of the committee established to discuss this and other matters relevant to assisted conception, Mary Warnock, opted for an approach that would grant respect to the different moral feelings and beliefs represented on her committee, and, she believed, in society more generally. John Harris (1985), among others (see for instance Wilson 2014, Ch 4), criticised Warnock's approach and argued that not all feelings should be considered *moral* feelings. Colouring Warnock's and Harris' normative views on whether human embryo research should have been allowed was not only a disagreement on this question. Rather, this disagreement rested on a differing meta-ethical commitment to which views and beliefs should be rightly included in the ethical debate on embryo research and on how to appraise these views and beliefs. It was a disagreement about meta-ethics prior to being a disagreement about normative ethics. Another example from the U.K. debate over embryo research concerned the role of moral philosophers in public policy, the question of moral expertise, and how to solve moral disagreement. Peter Singer (1972) and Richard M. Hare (1977) championed the role of philosophers as those able to provide authoritative answers to contested ethical matters. However, Warnock believed that bioethics was a sort of enterprise where "representatives of different groups and professions sought 'a middle way' between competing interests" (Wilson 2014: 161). Her role as chair of the committee appointed to deliberate over embryo research and assisted conception, but also as a philosopher, was to facilitate this process. At the heart of that debate on moral expertise and moral disagreement<sup>25</sup> were different meta-ethical views. In addition to these examples of the importance of underlying meta-ethical views among those who participate in bioethics debates, as argued by Garrard and Wilkinson (2003):

[M]uch of "folk" ethics is itself theory-laden. In other words, ordinary people's thoughts about morality are often driven by metaethical assumptions and so, in

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<sup>25</sup> At the heart of contemporary debates on these questions, see for instance David Archard (2011), Sarah McGrath (2008), and Madison Powers (2005).

## Who Should Come into Existence?

order to engage with these first-order views, it is necessary to engage with the metaethical assumptions lying behind them. (Garrard & Wilkinson 2003: 42)

In my view, all the sources I have described can enrich ethical reflections on new reproductive technologies. Some of these sources, such as empirical data on the experiences of couples whose embryos are undergoing PGD or philosophical reflections on well-being and political freedom, bring in something of direct relevance to the ethical assessments of new reproductive technologies and to how they should be regulated. Other sources are relevant to the debate in a more tangential and indirect manner: they may bring in the complexity described and welcomed by Nagel (1979); they may challenge certain assumptions of those participating in these debates; they may help to reconsider certain views and values; or, something I would hope for, foster the mutual understanding of and respect for those holding different moral beliefs. Hence, while I find Hedgecoe's (2004) and others' pledges for a critical bioethics very important, I do not agree that all bioethics needs is the social sciences and the adoption of a critical attitude. Debates on who should come into existence and how to balance the burdens and benefits of such decisions do need insights from the social sciences but also a lot more input from philosophy<sup>26</sup>, moral and social psychology, STS scholarship, and history. My hope is that the research that led to this thesis and to the papers incorporated into it represents a small step in that direction.

## 2 Scope: Which Technologies

Before moving to the outline of this thesis, a word is due on what I mean by 'new reproductive technologies' and which technologies I discuss in this thesis. I must be candid about this: not all the technologies discussed in this thesis are reproductive, not all of them are new, and not all of them are technologies. This is not some sneaky

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<sup>26</sup> Together with Garrard & Wilkinson's (2003) and Julian Savulescu's (2015) pleas for bioethics' need of moral philosophy, another interesting 'argument for' philosophical engagement is in Tim Lewens (2015). There, Lewens recommends an assessment of "the biological foundations of bioethics" (Lewens 2015: 3) and the incorporation of ethical analysis reflections and conceptual analyses from the philosophy of biology scholarship (Lewens 2015: 2-8) as "ethical discussion often draws on contentious interpretations of apparently biological facts" (Lewens 2015: 3).

way to violate Aristoteles' principle of non-contradiction, but to say that throughout this thesis I rely on a broad understanding of the terms 'reproductive', 'new', and 'technology'. Please allow me to explain.

I would usually define reproductive technologies, as the term suggests, as technologies that allow people to reproduce. More specifically, they give the opportunity to people that would not, that would not want to, that could not reproduce otherwise to try to reproduce. In this sense, the reproductive technology par excellence is in vitro fertilization (IVF): thanks to IVF, people suffering from infertility, those who need donor gametes due to infertility or hereditary conditions, who have frozen their oocytes to have children later in life, and others can have the chance to try to have genetically related (or partially genetically related) children. IVF is not new: the first person born through this technology is now giving talks, publishing books and, at the time of writing, has just turned 40. Since the birth of Louise Brown, IVF has gone a long way. By February 2015, when I was beginning my project, a quarter of a million babies had been born in the U.K. due to IVF since its implementation in this country in 1978 (Press Association 2016). Despite its long history, this and other technologies that I discuss in this thesis can be employed for purposes hitherto not possible or that they were not originally designed to serve. When IVF was first brought into the fertility clinics, it was meant to help couples experiencing fertility issues to become parents (Wilson 2014). Since then, though, its uses have changed significantly: now IVF is employed by single reproducers relying on gamete donors to become parents; by same-sex couples to have children who are genetically related to one of the couple (and sometimes gestationally related to the other, in the case of lesbian couples); it is employed to transfer embryos to the wombs of women acting as gestational surrogates; and to implant previously frozen embryos in the wombs of the genetic grandmothers of future children. So, while IVF itself is not new, some of its uses are.

Another technology that features in this thesis is PGD. The first clinical births following the application of PGD to in-vitro human embryos date back to 1990 (Handyside et al. 1992), and PGD is now being increasingly allowed in countries such as Italy that banned it for decades (for a discussion of the Italian context, see,

for instance, Biondi 2013). Despite this, the list of conditions eligible for PGD in the U.K. is frequently updated<sup>27</sup>. As the section of the Human Fertilisation and Embryology Authority (HFEA) website dedicated to PGD reads: “PGD is an area of medicine that’s changing very quickly”<sup>28</sup> due to progress in genetic knowledge and technical capacity. In this thesis, the label of ‘new’ attached to reproductive technologies may refer to the novelty of the technology (as in the case of MRTs); to the novelty of uses of a technology (as in the case of PGD), or to the novelty of a debate on a certain technology that has been hitherto used (as in the case of genome editing technologies).

Now that I hope I have settled what I mean by ‘new’, I turn to the meaning of ‘reproductive’ within the ‘new reproductive technologies’ label. PGD can be conceived of as a technology, but is PGD a *reproductive* technology? PGD is a technology that allows people who are known carriers of genetic conditions or who are directly affected by genetic conditions to test their IVF-produced embryos. Testing these embryos can reveal whether they have mutations that can give rise to the prospective parents’ condition(s). Many of the conditions eligible for PGD are not incompatible with life, i.e. the embryos could go on to develop into fetuses and subsequently children. Hence, PGD seems to be a testing technology rather than a reproductive technology in the same sense as IVF. In a broader understanding of the term, however, PGD contributes to the satisfaction of people’s procreative projects by allowing them to have children who are genetically related to them (or to one of them) and that do not carry their own genetic mutations. Some people may not want to reproduce knowing the risk of passing their conditions to their children or may be less willing to do so, making PGD instrumental to their procreative projects. Something similar can be said about genome editing technologies, which I discuss in several of the papers incorporated into this thesis (Cavaliere 2018a, 2018c; Cavaliere et al. 2019). Genome editing technologies such

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<sup>27</sup> The list is available at: <https://www.hfea.gov.uk/pgd-conditions/> (last accessed: 06 June 2018).

<sup>28</sup> Retrieved from the Human Fertilisation and Embryology Authority (HFEA) website at: <https://www.hfea.gov.uk/treatments/embryo-testing-and-treatments-for-disease/approved-pgd-and-ptt-conditions/> (last accessed: 07 June 2018).

as CRISPR (clustered regularly interspaced short palindromic repeats) could be employed to ‘edit’ the genome of early embryos in order to ‘correct’ harmful genetic mutations<sup>29</sup>. Genome editing technologies are not reproductive in the strict sense of the term outlined above, but arguably they are technologies that allow, directly and indirectly, people to fulfil their procreative projects. It is for this reason that I refer to them as reproductive technologies<sup>30</sup>.

An object of this study is also research involving human embryos, the practice that departs the most from the ‘new reproductive technologies’ label. Despite needing the aid of technologies to be carried out, embryo research is best understood in terms of a practice that, as Warnock declared<sup>31</sup>, allows for the development and the improvement of other reproductive technologies such as IVF and PGD. It is once again instrumental to procreative and parenthood projects and is hence, albeit indirectly, a reproductive technology.

What then do these ‘new reproductive technologies’ have in common? What justifies treating them as a unified, though heterogenic category? They have two main common features which serve as inclusion criteria: firstly, they are often labelled ‘eugenic’ within debates in bioethics and they indeed are, in my understanding of the term, *eugenic* technologies. Secondly, they create moral disagreement, sometimes “deep moral disagreement”: namely, the kind of disagreement persisting “even in ideal conditions, among fully informed, fully rational discussants” (Doris & Plakias 2008: 305). These technologies are eugenic in that they play a role in decisions concerning who should come into existence and about how to balance the burdens and benefits of such decisions. As is made clear in

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<sup>29</sup> This is currently not possible, but it is a possibility that I discuss in detail in Paper 3 (Cavaliere 2018a).

<sup>30</sup> Contrary to genome editing, MRTs are more faithful to a traditional understanding of the label ‘new reproductive technologies’. They were developed in the last few years; they have recently received the green light for clinical applications in the U.K., and they allow women who are known carriers of mtDNA mutations and conditions to have children who are genetically related to them without risking transmitting faulty mtDNA to these children. Paper 4 (Cavaliere & Palacios-González 2018) focuses in detail on these technologies.

<sup>31</sup> As I discuss in the third part of this thesis, Warnock argued that there could not have been IVF without embryo research as only the latter would have guaranteed that the former would be safe and efficacious (Wilson 2014).

the first, second, and third parts of my thesis, moral disagreement, and sometimes deep moral disagreement, surrounds them.

### 3 Structure and Outline of the Thesis

This is a cumulative PhD thesis that incorporates several published papers<sup>32</sup>. Parts I, II, and III incorporate two papers each. Of these papers, five have appeared in peer-reviewed journals and one is a chapter in an edited volume.

Other than these two papers, Parts I, II, and III each consist of an introduction and a conclusion that expands on the arguments developed in the papers and that brings together the reflections, claims, and assessments embedded in them. Part IV is a significantly edited and expanded version of a paper that, at the time of submission of this thesis (November 2018), I had just submitted for review to *Monash Bioethics Review*. The thesis ends with a general conclusion outlining how the research questions presented in this introduction have been addressed.

This thesis begins with an analysis of authors' discussions of the ethics of new reproductive technologies within bioethical debates on them, which is the object of Part I. There, I firstly focus on authors' ethical assessments of new reproductive technologies which explicitly refer to eugenics. I discuss the implications of employing the word 'eugenics' and of referring to this phenomenon within debates on new reproductive technologies. My argument is that competing assessments of the ethics of today's reproductive technologies mirror some of the disagreements and the competing assessments of the past. I then move on to survey and evaluate the strengths and the weaknesses of some of the argumentative strategies employed by authors participating in debates on the ethics of genome editing. Two papers

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<sup>32</sup> The publications' formatting, footnote numbering, and reference styles have been changed to match the style of the rest of the thesis. Other than that, the text has not been changed. As a result, some cross-references (in footnotes or in the body of the papers) may refer to sections or footnotes whose numbering has been changed. The original versions of each of the publications are enclosed in the Appendix.



(Paper 1, Cavaliere 2018d, and Paper 2, Cavaliere 2018c) are incorporated into this part of the thesis, and each of them explores one of the themes just outlined.

Part II of this thesis focuses on ethical questions raised by new reproductive technologies and, in particular, by MRTs and genome editing technologies applied to early human embryos. I discuss whether these technologies can be considered eugenic in the sense described in this introductory section and then move to two of the most debated issues in relation to these and reproductive technologies more generally: reproductive freedom and the preference to have genetically related children. These issues are dealt with in Paper 3 (Cavaliere 2018a) and Paper 4 (Cavaliere & Palacios-González 2018), which focus respectively on employing genome editing instead of PGD and on the use of MRTs to allow lesbian couples to have children who are genetically related to both parties. I conclude Part II with a reflection on the normative implications of satisfying people's preference to have genetically related children.

I then move from ethical questions raised by new reproductive technologies to ethical questions raised by the governance of these technologies. I begin Part III of the thesis with a discussion of the deliberative democracy framework. I then outline some of the ethical questions that become relevant when we move from theoretical-ethical debates to debates about the governance of new reproductive technologies. Two papers are incorporated into this part of the thesis (Paper 5, Cavaliere 2017, and Paper 6, Cavaliere et al. 2019). Paper 5 addresses the question of extending the statutory time limit to conduct research on human embryos, while Paper 6 focuses on ethical questions of regulating genome editing applications to human embryos within a framework informed by deliberative democracy.

In the last part of this thesis, I broaden my discussion from social, ethical, and political questions concerning new reproductive technologies to questions concerning the ethics of procreative decisions and procreation more generally. Within this thesis, I use the adjective 'reproductive' and the noun 'reproduction' to refer to activities aimed at bringing children into existence with the aid of technologies. I use these terms when these activities are carried out by and oriented towards *individuals* and when the rights, preferences, and interests of individuals are

at stake. In contrast, I employ the adjective ‘procreative’ and the noun ‘procreation’ to refer to these activities more generally, i.e. not only when they are carried out with the aid of reproductive technologies. I also employ them to refer to the cumulative and wide-reaching aspects of these activities and to the resulting broader rights, preferences, and interests at stake<sup>33</sup>. In Part IV, I show that debates on new reproductive technologies are often informed by an individual-centred framework, such as that underpinning reproductive freedom. This framework focuses chiefly on individual (i.e. the procreators’ and their close networks’) interests. Authors with different ethical concerns and different proposals to address these concerns criticise reproductive freedom and its individual-centred framework. I argue that while the individual-centred framework may be inadequate to discuss ethical questions raised by procreative decisions, these authors’ arguments and proposals present a number of epistemic and ethical shortcomings.

#### 4 Coda

Before bringing this introduction to a close, I wish to briefly return to some of the key themes of this thesis and of the research that led to it. The real protagonist of the thesis is eugenics in the broad understanding of this concept outlined above. A study of 20<sup>th</sup> century eugenics and especially of the role of this history and of references to this history within debates on the ethics of new reproductive technologies (Parts I-III) and of procreative decisions (Part IV) can help to shed light on authors’ competing assessments of today’s technologies and, I will argue, eugenics can reveal more than it obscures. Today’s debates on new reproductive technologies and on procreative decisions re-enact some of the complexities, themes, and ethical dilemmas that were part of 20<sup>th</sup> century eugenics. Many of these debates revolve around questions pertaining to the quest to improve the human gene pool, to have children who are healthy and who are genetically related to their parents, to the ethical standing of this preference, to the role of the state, and of

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<sup>33</sup> With respect to reproductive freedom instead, I use this expression throughout the thesis and I do not distinguish between reproductive freedom and other expressions used to refer to this concept: such as reproductive autonomy and John A. Robertson’s (1983) original procreative liberty.

## Introduction

third parties' interference in such decisions. It may be tempting to dismiss the relevance of the analogies between past and present or to make too much of them. This thesis seeks to find a middle-ground between these two endeavours. It seeks on the one hand to find ways to contribute (methodologically) to debates on these questions, and on the other to find ethical ways to address questions concerning the ethics of eugenics in theory and in practice.

# PART I

## Discussing the Ethics of New Reproductive Technologies

### 1 Introduction to Part I

The object of this part of the thesis is a *reflection on and an analysis of* the arguments, claims, and assessments of authors participating in debates on the ethics of new reproductive technologies. Hence, my focus here is on *discussions* about the ethics of new reproductive technologies rather than on ethical questions raised by new reproductive technologies proper (the object of Part II). As I mentioned in the introduction to this thesis, debates on the ethics of new reproductive technologies share two features: the first is that they can be conceived of as debates on the ethics of eugenics due to these technologies' instrumental role in decisions concerning who should come into existence; the second is that these debates are characterised by moral disagreement among a relatively wide and diverse range of actors<sup>34</sup>. The present analysis hinges on these two issues and focuses respectively on the references to eugenics within debates on the ethics of new reproductive technologies (in Paper 1, Cavaliere 2018d) and the different argumentative strategies employed by authors participating in debates characterised by moral disagreement (in Paper 2, Cavaliere 2018c).

This part of the thesis incorporates two papers. Paper 1 (Cavaliere 2018d) is a single-author paper published in *Monash Bioethics Review* titled 'Looking into the Shadow: The Eugenic Argument in Debates on Reproductive Technologies and Practices'. In this paper, I use references to the history of eugenics within debates on the ethics

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<sup>34</sup> Although my analyses and reflections concern debates among bioethics scholars, moral disagreement does not only arise within this group. Moral disagreement arises among scientists developing these technologies, journalists reporting on them, members of the public directly involved as users, members of the public tangentially involved due to the potential effects on societal norms and values of their introduction, policy-makers, and members of ethics committees.

of new reproductive technologies as a case study. I reflect on and analyse the arguments, claims, and assessments which authors employ in normative discussions on these technologies. Paper 1 introduces several of the key themes of this thesis, including the controversy over the use of the word ‘eugenics’ and the relevance of the history of eugenics within ethical debates on new reproductive technologies. It also shows how authors juxtapose new reproductive technologies with past eugenics and the implications of this for their assessments of these technologies’ ethical standing. Finally, Paper 1 addresses the first of the two research questions that guided my analysis of debates on the ethics of new reproductive technologies, namely the question concerning the role of the reference to eugenics within debates on the ethics of new reproductive technologies.

Paper 2, also incorporated into this part of the thesis, is titled ‘A Path Through the (Moral) Morass: Genome Editing, Reproduction and Broad Conversations’ (Cavaliere 2018c). It is a chapter of a volume titled *Between Moral Hazard and Legal Uncertainty. Ethical, Legal and Societal Challenges of Human Genome Editing* (edited by Matthias Braun, Hannah Schickl, and Peter Dabrock). In this paper, I use the debate on genome editing as a case study for my analysis of arguments, claims, and assessments advanced within debates on the ethics of new reproductive technologies. As I argued in the introduction to this thesis, I consider genome editing technologies an instance of reproductive technologies due to their role in allowing prospective parents to pursue their procreative projects. Paper 2 addresses the second research question concerning debates on the ethics of new reproductive technologies by analysing the argumentative strategies employed within these debates and by reflecting on ways to tackle the moral disagreement that surrounds these technologies.

Both papers exemplify how competing values and beliefs inform authors’ assessments of the ethics of new reproductive technologies, and how references to eugenics cut across such assessments. Part I thus sets the foundations to investigate the central question of this thesis: who should come into existence? New reproductive technologies confront us with this question and raise several ethical challenges. Analysing normative debates on these technologies represents a first step

towards addressing the question of who should come into existence and towards thoroughly assessing these challenges.

Turning back to the two aims of this project outlined in the introduction, in this part of the thesis I seek to pursue the methodology-oriented aim to contribute to making these debates more inclusive in terms of different disciplinary sources and to adopt a critical and reflective gaze on some of the argumentative strategies employed in these debates. This analytic work also seeks to lay the groundwork for addressing the other aim of this project, which pertains more specifically to the question of who should come into existence<sup>35</sup>.

### 1.1 Underlying Causes of Moral Disagreement: A Matter of Values

Reproductive technologies raise questions which, for many, are strictly linked to deep-seated values and moral beliefs<sup>36</sup>. The disagreement that surrounds them is hence ‘moral’ in that it pertains to these values and beliefs. Following John M. Doris and Alexandra Plakias (2007), this disagreement can often be characterised as ‘deep’ because authors discussing under ideal conditions (namely “fully informed and fully rational discussants”, Doris & Plakias 2008: 305) may still disagree.

In the three years of my work on the project that led to this thesis, two new reproductive technologies, MRTs and genome editing technologies’ applications to early human embryos, have attracted ethical interest and controversy. They have been at the centre of heated debates on questions concerning their ethical standing

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<sup>35</sup> To recap, the second aim of this project is to provide arguments and to suggest strategies to make new reproductive technologies more widely accessible, regulated in ways which fairly distribute the burdens and benefits of decisions of who should come into existence, and implemented in ways which consider the plurality of values of those directly and indirectly affected by these technologies.

<sup>36</sup> Just to name a few, these technologies raise ethical questions concerning the value of early human life and personhood (Harris 1985); the value of genetic relatedness (Overall 2012; Rulli 2016b); the just allocation of scarce resources (Rulli 2016a), among others. These technologies have the potential to redefine the meaning of personhood (Novas & Rose 2000); the ‘future of kinship’ (Franklin 2013); the desire to have genetically related children (Lesnik-Oberstein 2007) and the wish to enact different ‘ethical futures’ (Dimond & Stephens 2018b, Ch 7).

and how to regulate them<sup>37</sup>. In 2015, the U.K. became the first country in the world to approve the clinical use of pronuclear DNA transfer (PNT) and mitochondrial spindle transfer (MST), which I collectively refer to as MRTs<sup>38</sup>. MRTs give women carrying mtDNA mutations the theoretical possibility to have children who are genetically related to them and will not inherit the mutations that they carry, which can often lead to harmful conditions<sup>39</sup>. Authors have debated the ethical standing of employing these technologies and focused on questions such as whether women carrying mtDNA mutations should explore alternative avenues to pursue their parental projects (e.g. Baylis 2017a; Rieder 2015a; Rulli 2016a); whether clinical research and applications of MRTs should be prioritised over other medical endeavours in terms of resource allocation (Rulli 2016a); whether access to these technologies should be granted only to women carrying mtDNA mutations or also to other women (Cavaliere & Palacios-González 2018); whether they were and are ‘safe’ or ‘safe enough’ to proceed (Harris 2016a; de Melo-Martín 2017b); how they should be labelled (Baylis 2017a, 2018; Dimond & Stephens 2018a; Ravitsky et al. 2015; Cavaliere & Palacios-González 2019); whether they should be classified as instances of germline gene therapy<sup>40</sup> (Newson & Wrigley 2017); whether there are significant moral differences between PNT and MST (Palacios-González 2017a; Wrigley et al. 2015); whether one or both of these technologies amount/s to eugenics and what ethical implications this distinction entails (Wrigley et al. 2015), among other ethical questions<sup>41</sup>.

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<sup>37</sup> For an excellent account of the U.K. debate on MRTs, of the key actors involved in this debate and of the steps that have led to the approval of these techniques in the U.K., see Rebecca Dimond and Neil Stephens (2018b).

<sup>38</sup> Below, I return to this label (and abbreviation) and show that is contested within debates on the ethics of these technologies.

<sup>39</sup> Other techniques which can be used to the same end are: first polar body transfer and second polar body transfer. At the time of writing, however, the only techniques allowed were PNT and MST.

<sup>40</sup> See also Rosamund Scott and Stephen Wilkinson (2017) for a discussion of the label ‘germline genetic modification’ within policy debates and reports in the U.K. and the U.S.

<sup>41</sup> Other ethical questions are discussed throughout the thesis or referenced in footnotes. Questions which I do not explicitly address include: whether mtDNA donations should be anonymous (Appleby 2017; Brandt 2016); whether they worsen potential and actual harms to egg providers (Baylis 2013) and whether only male embryos should be selected (Appleby 2015). For an overview and discussion of ethical questions raised by MRTs, see for instance: John Appleby (2015); Annelien Bredenoord et al. (2011); Annelien Bredenoord and Peter Braude (2010) and Ainsley Newson et al.

Advances in genome editing technologies and the application of one of them (CRISPR) to non-viable human embryos sparked a debate on the ethical standing of inserting inheritable changes into the genetic makeup of early embryos, and on questions concerning regulatory and public engagement strategies<sup>42</sup>. Despite the differences between MRTs, genome editing technologies<sup>43</sup> and other new reproductive technologies discussed throughout this thesis, the ethical debates and, to a certain extent, the arguments advanced by authors who took part in these debates have been remarkably similar. Within the ethical debate on synthetic biology, Hurlbut (2015) has negatively characterised this apparent lack of ethical imagination as “patterned and institutionalized” (Hurlbut 2015: 115). Echoing this view and writing about the ethical debate on genome editing, Nathaniel C. Comfort (2015) has described such debate as “familiar to a historian” and following “the classic arc of breakthrough methods in genetics and biotech”, where:

[F]irst come millennialist debates over the new eugenics; then, calls for caution. A few cowboys may attempt rash experiments, which often fail, sometimes tragically. Finally, the technology settles into a more humdrum life as another useful tool in the biologist’s kit. (Comfort 2015)

Historians such as Comfort (2015) and Hurlbut (2015) correctly show similarities among these debates across time and technologies (in terms of recurrent modes of reaction to new technologies). Despite this, my analysis of debates on the ethics of new reproductive technologies shows that the problem is not that authors discussing the ethics of new reproductive technologies have exhausted all the arguments and with them their ethical imagination. What makes reactions to new (reproductive) technologies similar across different debates is that the disagreement stems from the different underlying values and ethical views held by authors participating in these

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(2016). See also Erica Haines and Ken Taylor (2017) for a discussion of the debate on MRTs and a problematisation of the claims concerning the benefits of these techniques.

<sup>42</sup> The recently published (July 2018) Nuffield Council on Bioethics report *Genome editing and human reproduction: social and ethical issues* contains a discussion and assessment of both these questions (Nuffield Council on Bioethics 2018). I discuss these questions in Paper 6 (Cavaliere et al. 2019).

<sup>43</sup> The ethical debate around genome editing technologies is described and assessed in Paper 2 (Cavaliere 2018c) and Paper 3 (Cavaliere 2018a).



debates. These competing values and ethical views are, as it were, carried from debate to debate, as there is no agreement across authors and members of society concerning what Derek Parfit (2011) aptly defined as ‘what matters’. Debates about new reproductive technologies certainly revolve around the ethical questions briefly outlined above and discussed in the papers incorporated into this thesis. Despite this, these debates are also concerned with values such as people’s freedom, equality of opportunity, justice and the value of ‘accepting the given’ (Cohen 2004); they are concerned with what, if any, of these values should be given priority in practice, and with what acting upon these values entails.

Examples of the negotiation of competing values and world-views emerge from an observation and an analysis of the arguments advanced by authors concerning the relationship between 20<sup>th</sup> century eugenics and new reproductive technologies. As I discuss in Paper 1 (Cavaliere 2018d), authors who refer to eugenics within debates on these technologies often do not ground their arguments about both condemnable features of the past and condemnable and justifiable features of the present in in-depth historical analyses (Bashford 2010; Paul 1998). In their accounts, eugenics is condemned and considered as something that ought not to be repeated but this is often without any (or little) engagement with the complexities of its historical unfoldings. Another common feature of authors’ references to eugenics within debates on the ethics of new reproductive technologies is that they broadly agree that 20<sup>th</sup> century eugenics was ethically troubling (Bashford 2010; Buchanan et al. 2001). They also agree that if new reproductive technologies, their application and the rationale guiding their development and implementation embody ethically troubling features such as those that characterised eugenics, then, all else being equal, there are good reasons to condemn them. The problem, and the disagreement, arises on the one hand with respect to which features of 20<sup>th</sup> century eugenics these authors consider more ethically troubling than others and, on the other, with respect to whether they consider these features ethically troubling at all. For instance, while many authors condemn the coercive character, the focus on the population rather than on the individual and the violation of bodily integrity of 20<sup>th</sup> century eugenics (Agar 2008; Glover 2006; Savulescu & Kahane 2009), others

consider its chief moral wrongs to reside in its quest for genetic improvement<sup>44</sup> and perfection (Garland-Thompson 2012; Sandel 2004a). These diverging assessments of the ethics of 20<sup>th</sup> century eugenics result in disagreement about which features of the present (i.e. of new reproductive technologies) are problematic and which, in turn, are not problematic or are less so<sup>45</sup>. Those focusing on the problem of coercion, population-wide interventions and violation of bodily integrity see new reproductive technologies as a positive development as they can be freely chosen by prospective parents. By contrast, those who see the problem with eugenics as the quest for genetic improvement and perfection condemn new reproductive technologies as they regard them as embodying and being motivated by similar aims.

In short, the moral disagreement about what went wrong (and what went, to a certain extent, right) in the past mirrors authors' views of what is troubling or acceptable in the present. My view is that these diverging assessments of past and present can be explained by the conflicting values which motivate these assessments. What authors disagree about are the ethical standing of values and beliefs grounding eugenics and which ground the developments, implementations and rationales for new reproductive technologies. In other words, what authors disagree about is not only whether new reproductive technologies embody 20<sup>th</sup> century eugenics' ideas, practices and policies and should hence be considered morally troubling; rather, what divides them is whether during the 20<sup>th</sup> century as today the negotiation of values involved in the idea of deciding who should come into existence and in the implications of these decisions withstands ethical scrutiny. Without an explicit and comprehensive account of the history of eugenics, the process whereby conflicting values and world-views about new reproductive technologies are discussed and weighed-up cannot be obtained.

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<sup>44</sup> For an ethical appraisal of this aim, see for instance Wilkinson (2010, Ch 6) and Buchanan et al. (2001, Ch 2).

<sup>45</sup> As I show in Part IV, the disagreement about the troubling nature of certain features of 20<sup>th</sup> century eugenics matters also for debates on the ethics of procreative decisions and procreation more generally. Within these debates, authors who single out 20<sup>th</sup> century eugenics' coercive character and its population-level *modus operandi* as eugenics' most despicable features, often find in reproductive freedom and non-interference on the part of the state a possible solution to avoid re-enacting past wrongs.

## 1.2 Moral Disagreement, Terminology, and Argumentative Strategies

The disagreement about the values underpinning eugenics and new reproductive technologies extends to disagreement about the appropriate terminology to describe these latter. For instance, authors discuss whether the word ‘eugenics’ should be used at all in reference to reproductive technologies (see for instance: Camporesi 2014; Koch 2004; Wilkinson 2008). Similarly, within the debate on the ethics of MRTs part of the disagreement that surrounds these technologies revolves around the question of the appropriate terminology (and abbreviation) to refer to them (Baylis 2017a, 2018; Loike 2014; Palacios-González 2016; Cavaliere & Palacios-González 2019; Ravitsky et al. 2015) and around the mobilisation of emotions through emotive language<sup>46</sup> (Dimond & Stephens 2018a; Ravitsky et al. 2015). Both whether the word ‘eugenics’ should be used at all, and the terms and language which should be employed to describe MRTs can be interpreted as disputes<sup>47</sup> whose implications are normative<sup>48</sup>. As Simon Blackburn (1998) argues, certain words:

[A]re contested because they illustrate attitudes, and have other consequences, and these can rightly cause concern. [...] Words typically nudge people, with more or less subtlety, towards attitudes to the things they pick out. (Blackburn 1998: 15)

Individual words, expressions, metaphors, discourses and other syntactic and rhetorical tools have the potential to redirect people’s interests (Stevenson 1937), to

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<sup>46</sup> Dimond and Stephens (2018a), for instance, describe how the MRT debate features ‘vivid imaginaries’, including: ‘dystopian predictions’ about ‘slippery slopes’ and ‘crossing a line’ (Le Page, 2015), ‘designer babies’ (Hills, 2012), ‘Frankenstein science’ (McKie, 2014) and emotive themes such as ‘playing god’ and stopping children suffering (Driscoll, 2015)” (Dimond & Stephens 2018a: 6). They also argue that “language and representations matter because their use can be political” (Dimond & Stephens 2018a: 6) and how using the metaphor of a battery to describe mitochondria is “an important component of the discourse surrounding mitochondrial donation, as it performs the important work of enabling the technology to be positioned as unproblematic” (Dimond & Stephens 2018a: 6). See also Sarah Chan (2016); Ilke Turkmendag (2018) and Dimond and Stephens (2018b: 52-54) on this issue.

<sup>47</sup> These are disputes in which I have been caught-up too. See Françoise E. Baylis’ (2018) reply to Paper 4 (Cavaliere & Palacios-González 2018) and César Palacios-González’s and my subsequent reply (Cavaliere and Palacios-González 2019).

<sup>48</sup> See also: footnote 47 on how the use of certain language and metaphors can be used for political ends (Dimond & Stephens 2018a).

“mediate public understanding of the innovations” (O’Keefe et al. 2015: 3), to “win the allegiance of large groups of people” to specific policies (Schön & Rein 1994: 32) and a “capacity to act” (Dimond & Stephens 2018b: 53). Moreover, within debates on new reproductive technologies studies have shown a correlation between the words employed to describe screening technologies such as PGD (Wilkinson 2008), MRTs (Ravitsky et al. 2015) and gene editing technologies (O’Keefe et al. 2015), and the normative position of the person who employs them. Those who oppose these technologies are more likely to use terminology which emphasises the risks, the uncertainties and the resemblance to widely condemned practices such as eugenics; whilst those in favour of these technologies are more likely to use expressions and wording that emphasise the benefits while dismissing potential risks and harms<sup>49</sup>.

The literature on ‘framing effects’<sup>50</sup> shows why the decisions to employ certain terminology has normative implications. As I discuss in Paper 1 (Cavaliere 2018d), studies in social and moral psychology reveal that people’s (moral) judgements can be influenced by employing a certain word rather than another (or by ordering the wording in a sentence in different ways). Following this idea, people’s judgements are subjected to word-type framing effects if their ethical assessments of a given reproductive technology depend on the way the technology is described, on *which kind of words* are used to describe it, rather than on the technology and its applications. Describing a technology as eugenics (considering what eugenics is often associated with) frames people’s judgement regarding the technology in question and may influence their ethical assessment of it<sup>51</sup>.

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<sup>49</sup> See also Brian P. Bloomfield and Theo Vurdubakis (1995) on this issue.

<sup>50</sup> See for instance Jonathan Haidt and Jonathan Baron (1996); Jonathan Haidt and Fredrik Björklund (2007); George Lakoff (2004); Lewis Petrino and Patricia O’Neill (1996); Walter Sinnott-Armstrong (2007).

<sup>51</sup> ‘Frames’ and ‘framing’ are concepts used within policy interpretation and analysis too. Within this context, framing is intended as a “way of representing knowledge, and as the reliance on (and development of) interpretative schemas that bound and order a chaotic situation, facilitate interpretation and provide a guide for doing and acting” (Laws & Rein 2003: 173). For an interpretation and an overview of ‘policy frames’ see for instance Martin Rein and Donald A. Schön (1996).

Normative questions pertaining to the appropriate use of rhetoric in political debates, and argumentative and persuasive strategies date back to the work of Plato (especially in *Gorgias* and *Phaedrus*) and Aristoteles (who discussed the role of passions in rhetoric in his treatise *On Rhetoric*). A review of their work and of those others in philosophy who have attempted to set out rules and prescriptions of what should be rightfully part of rhetoric is beyond the scope of this thesis<sup>52</sup>. What I discuss in reference to eugenics and new reproductive technologies is instead whether the word ‘eugenics’ should be employed at all within debates on these technologies, considering the potential of the word to elicit negative emotional responses<sup>53</sup>.

With respect to the normative question of whether employing the word ‘eugenics’ and other instances of emotive language should be avoided in debates on new reproductive technologies, I occupy a middle ground. In my view, the terminology employed in these debates should strive for conceptual clarity and descriptive accuracy. As I discuss in Paper 1 (Cavaliere 2018d), the reference to eugenics within debates on the ethics of new reproductive technologies is often employed without thorough engagement with the history of eugenics and devoid of an exercise of unpacking and clarifying its negative connotations (Paul 1992). Hence it often reads as the expression of unease, refusal and undetermined condemnation. It lacks both descriptive and normative elements which allow authors who participate in debates on the ethics of new reproductive technologies to engage with each other’s arguments and with the values driving them. In my view (and as I argue in Paper 1), the problem with ‘loaded words’ such as ‘eugenics’, then, is not that they represent an obstacle to sound and impartial reasoning due to their emotive components. Within moral psychology, studies on emotions and intuitions show that it is a

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<sup>52</sup> For a recent discussion of the role of passions in rhetoric in relation to the work of Aristoteles, see Jamie Dow (2015). Another discussion of Aristoteles’ work on rhetoric is in Herbert Gottweis and Barbara Prainsack (2006). Gottweis and Prainsack are concerned with debates on regulating human embryonic stem cell research in the U.S., the U.K., Germany, and Israel in light of Aristoteles’ categories of *ethos*, *pathos*, and *logos*.

<sup>53</sup> As discussed above, similar terminological/normative questions arise in debates on MRTs and on other reproductive technologies; see for instance Brigitte Nerlich, Susan Johnson, and David D. Clarke (2000).

combination of both calculating rationality and intuitions/emotions that is needed for moral cognition and reasoning<sup>54</sup> (Greene 2014; Haidt 2001, 2012). The use of words which arouse emotional reactions is not problematic per se, but it is if these words are employed misleadingly<sup>55</sup>, i.e. following the Oxford Dictionary definition of the adverb: ‘causing someone to have the wrong idea or impression’ of for instance the technology in question, and deceptively, i.e. ‘deliberately causing someone to believe something that is not true’, again concerning the technology that is discussed. Lastly, what would make the use of loaded words problematic is what Alberto Giubilini (2015) argues with respect to the debate on the ethics of human enhancement. According to him:

[M]aking reasons and underlying concerns explicit so that the ultimate moral or philosophical issues at stake [...] can be detected, unpacked, and rationally discussed, instead of remaining hidden and unexamined in intuitive and emotive responses. (Giubilini 2015: 46)

Deception, misleadingness and purely emotional appeals are what make the use of loaded words problematic: not necessarily their potential to arouse emotional reactions.

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In Paper 2 (Cavaliere 2018c), I address the question of the potential strategies to tackle moral disagreement within debates on the ethics of new reproductive technologies. I firstly present and discuss two hypotheses as to what the causes of moral disagreement on the ethics of genome editing (and, to a certain extent, on MRTs) could be. These two hypotheses trace the emergence and persistence of moral disagreement to factual disagreement and lack of philosophical skills. Rather

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<sup>54</sup> In recent years, findings in moral psychology have begun to show that moral judgements are informed by intuition and that the ideal of forming moral judgements with only the aid of a purely cold, calculating rationality is an illusion (Greene 2014) and perhaps a dangerous one (Damasio 1994). In particular, moral psychologists (Greene 2014; Greene et al. 2001; Pizarro 2000; Haidt 2001, 2012), neuroscientists (Damasio 1994) and philosophers (Nussbaum 2003) have provided empirical and theoretical evidence in support of the thesis that gives intuitions and emotions a role in the formation of moral judgements and, in certain cases, of the desirability thereof.

<sup>55</sup> Wilkinson (2008) discusses reasons to avoid words within the context of whether there are good, non-partisan reasons to avoid using the word ‘eugenics’ in debates on the ethics of PGD.

than representing my own views on the emergence and persistence of moral disagreement, these two hypotheses are inferred from my analytical and reflective work on argumentative strategies employed by authors participating in debates on the ethics of new reproductive technologies. These hypotheses capture what some of the authors participating in these debates seem to consider the causes of the disagreement as they channel time and energy in trying to persuade authors holding different ethical views that they are mistaken on factual and/or philosophical grounds.

The first argumentative strategy that these authors employ focuses on eliminating or reducing epistemically flawed understandings of the safety and efficacy of new reproductive technologies such as genome editing and MRTs. As I argue in Paper 2, while this is a worthy and important part of what authors should aim for, assessments of the facts of the matter are often informed by our own ethical views and values, and by the position in society that we find ourselves in. For these reasons (and others discussed in Paper 2), it seems that this strategy neither goes to the heart of the disagreement nor seems a good place to start to settle conflicting assessments of the ethics of new reproductive technologies. The second strategy is to construct arguments which are consistent, valid, and sound (in the philosophical sense of the terms), and at the same time to point to the fallacies of other authors' arguments. This also presents difficulties. While philosophical arguments and systematic reasoning can assist in the process of clarifying and refining the concepts, ethical challenges and values at stake, this analytical work is often not sufficient to settle the moral disagreement that characterises debates on the ethics of new reproductive technologies. Other than the procedural challenges I discuss in Paper 2 (Cavaliere 2018c), this strategy may engender undesirable normative implications. Authors such as Katrien Devolder (2015), with respect to the debate on the ethics of embryonic stem cell research, Dan W. Brock (1987) and Jonathan Wolff (2011), with respect to the role of (moral and political) philosophers in public policy, have argued that there could be good epistemic, practical and moral reasons to avoid this strategy when we move from theoretical-ethical debates to debates which have policy-oriented aims and implications. According to them, policies could be based on arguments which are philosophically flawed, do not progress towards the search for

truth and on ethical views that are widely shared and accepted rather than what would amount to the 'right' ethical view. This is not to say that arguments in debates on the ethics of reproductive technologies should not strive to be consistent, to be valid and sound, and to be grounded in what each author considers the right ethical view. Similarly, pointing to the fallacies of other authors' arguments is an endeavour that should be pursued. What I argue in Paper 2 is that aiming for philosophical validity, soundness and consistency, and criticising other authors' views for lacking these characteristics should not be the only endeavour pursued.



## 2 PAPER 1: Looking into the Shadow: The Eugenics Argument in Debates on Reproductive Technologies and Practices

Paper 1 is a single-authored paper published in *Monash Bioethics Review*.

The original version of this paper is enclosed in Appendix 1.

Cavaliere, G. (2018d). Looking into the shadow: The eugenics argument in debates on reproductive technologies and practices. *Monash Bioethics Review*, 36(1), doi: 10.1007/s40592-018-0086-x

### 2.1 Abstract

Eugenics is often referred to in debates on the ethics of reproductive technologies and practices, in relation to the creation of moral boundaries between acceptable and unacceptable technologies, and acceptable and unacceptable uses of these technologies. Historians have argued that 20<sup>th</sup> century eugenics cannot be reduced to a uniform set of practices, and that no simple lessons can be drawn from this complex history. Some authors stress the similarities between past eugenics and present reproductive technologies and practices (what I define throughout the paper as ‘the continuity view’) in order to condemn the latter. Others focus on the differences between past and present practices (what I define throughout the paper as ‘the discontinuity view’) in order to defend contemporary reproductive technologies. In this paper, I explore the meanings of the word ‘eugenics’ and the relationship between its past and present uses in terms of contemporary debates on reproductive technologies and practices. I argue that moral disagreement about present technologies originates in divergent views of condemnable and justifiable features of the past.

**Keywords:** Eugenics | Reproductive technologies | Coercion | Stigmatisation | Disability.

## 2.2 Introduction

New assisted reproductive technologies such as mitochondrial replacement techniques (MRTs), reproductive screening technologies such as pre-implantation genetic diagnosis (PGD), pre-natal diagnosis (PND) and non-invasive prenatal testing (NIPT), as well as gene editing technologies such as CRISPR (clustered regularly interspaced short palindromic repeats) incite ethical controversies<sup>56</sup>. They do so because procreating and raising children, and influencing the type and number of people who will inhabit our planet in the future, touch upon people's core moral beliefs and values. Partly for this reason, assisted reproductive technologies and practices engender moral disagreement and give rise to many highly controversial debates in bioethics. Examples of the questions discussed within these debates include whether or not technologies will bring about better or worse states of affairs compared to the status quo; whether their introduction will cause increased injustice, discrimination, sexism, ableism and racism or whether they will make our lives (or our children's lives) happier, healthier and/or longer. Some arguments focus on the consequences, and others concern the intrinsic goodness or wrongness of these technologies and their applications.

While the ethical questions discussed in these debates in academia, the media and other public fora are fairly diverse, one set of these questions has a common and recurrent feature: eugenics. This set of questions includes whether a given technology is eugenic; whether it might bring eugenics back and whether this possibility is something to be feared or welcomed. What is referred to as the "shadow of eugenics" (Buchanan et al. 2001: 27) – namely the collective memory of condemned practices such as forced sterilisations as well as the condemned science of heredity, shared systems of belief, policies and ideas of different actors – continues to permeate today's ethical debates on reproductive technologies and practices. As I show in this paper, some authors stress elements of discontinuity between past eugenics and contemporary reproductive technologies and practices, while others

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<sup>56</sup> Throughout the paper, if I am not referring to a specific technology or practice, I refer to all of them collectively as 'reproductive technologies or practices'.

focus on elements of continuity between past and present. Both groups agree on the wrongness of past eugenics, but they have different views on the relationship between past and present, and especially on the ethical standing of present technologies and practices. Authors who hold what I refer to as the “discontinuity view” between past and present defend reproductive technologies and practices, grounding some of their arguments in the differences between the latter technologies and the eugenic past, while those holding what I refer to as the “continuity view” condemn these technologies and practices, their arguments grounded in similarities with the past.

The content of the arguments underlying the discontinuity view varies slightly, but their form can be summarised as follows:

“Eugenics was intrinsically wrong because it entailed x, y, z; other things being equal, reproductive technologies and practices are not wrong because they lack x, y, z”.

Similarly, the content of the arguments of scholars who hold the continuity view varies slightly, but their form is homogeneous:

“Eugenics was intrinsically wrong because it entailed x, y, z; other things being equal, reproductive technologies and practices are wrong because they have elements of x, y, z”.

Considering that arguments drawing on the discontinuity and continuity between past and present are subsumed in the ethical assessments of reproductive technologies and practices, one would expect a knowledge of both the past and the present to play an important role in such assessments. In other words, considering that both arguments heavily rely on ‘x, y, z’, i.e. on problematic features of past eugenics to ground their condemnations or absolutions of reproductive technologies, one would expect their assessments to be supported by sound and detailed historical analyses<sup>57</sup>. However, this is not entirely the case. As I show in this paper, what

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<sup>57</sup> In addition to being informed about these technologies and practices’ technical characteristics, their potential applications, safety, efficacy, etc.

authors consider the capital sins of past eugenics vary greatly and many of their arguments about both the past and the present are not based on in-depth historical analyses (Bashford 2010; Paul 1998). Past eugenics is assumed to be something despicable that ought not to be repeated, but those who participate in debates on the ethics of reproductive technologies and practices often fail to explicitly refer to what was wrong with eugenics and why<sup>58</sup>. Furthermore, these arguments rely on accounts of the history of eugenics often limited to the practices carried out during Nazism, and to racist and coercive dimensions of eugenics policies and practices (Bashford 2010). Why is this the case? One potential answer is that there is a division of “*cognitive* labour” among academics ([emphasis in original] Kitcher 2011: 193), and: “a group of investigators, addressing a common problem, pursues different approaches to that problem” (Kitcher 2011: 193). Those who participate in debates on the ethics of reproductive technologies and who employ the arguments outlined above are often philosophers, theologians, sociologists, biotechnologists and so forth; they are rarely historians.

Before delving into the work of historians of eugenics and their influence on debates on reproductive technologies and practices, it is necessary to give a short statement on the structure of the paper. In the next section, I present the work of historians of eugenics and discuss how they have tried to bring to light the multiplicity of practices, policies and actors that characterised 20<sup>th</sup> century eugenics. Next, I focus on the meanings of the word eugenics and present some of the definitions which are used in debates on reproductive technologies to describe this phenomenon. I identify different strategies to describe eugenics and criticise the use of definitions that presuppose its moral wrongness. I then turn to what I define as the discontinuity and continuity views of the relationship between past and present. I discuss both views and show that they rely on different assessments of what was wrong in the past and that these assessments of the past play an important role in authors’ assessments of the present. My hope is that reflecting on the meanings of ‘eugenics’, on the relationship between past and present, and on the roles and the

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<sup>58</sup> With notable exceptions. See for instance: Buchanan (2007); Buchanan et al. (2001); Camporesi (2014); Gyngell and Selgelid (2016); Selgelid (2000); Wikler (1999).

understandings of eugenics will shed some light on its shadow and contribute to debates on the ethics of reproductive technologies and practices.

### 2.2.1 Where Are Historians When We Need Them?

In the comparison of reproductive technologies and practices to a historical phenomenon, eugenics, historians could help settle at least *some* of the questions that cause the moral disagreement among scholars participating in debates on their ethical standing, such as whether the similarities between past and present are so significant that the comparison is warranted. Many historians have indeed tried to make sense of the history of eugenics and to reconstruct it while taking into account its complexities, divergences and multifaceted aspects. It is therefore surprising that in debates on the ethics of reproductive technologies, the comparison with this past phenomenon is often made without reference to studies of the history of eugenics, and that the homogeneity of this past phenomenon is often taken as a given. For instance, Bennett (2014) calls Harris' and Savulescu's arguments in favour of using PGD to create the best possible child a 'eugenic vision'. Despite this, she fails to specify what she means by 'eugenic', to refer to the historical unfolding of this phenomenon and to its relationship with PGD and with the work of both Harris and Savulescu. Similarly, Savulescu and Kahane (2009), in their seminal work on procreative ethics and PGD, refer to eugenics in terms of 'moral atrocities' and of 'the collectivist, coercive and often racist projects of the 20th century' and conclude that the procreative principles that they have discussed 'bear little resemblance' with eugenics. Again, eugenics as a historical phenomenon is a point of reference devoid of its historical unfolding. As Koch (2004) argues:

[T]he witless reference to 'eugenics' with no further specification is empty and more often a function of our own projections and intentions than a reference to history. (Koch 2004: 329)

Historians and science and technology scholars have shown how eugenics, throughout history, cannot be easily reduced to a uniform set of practices and to a univocal ideology (Bashford 2010; Bashford & Levine 2010; Ekberg 2007; Kevles 1985; Koch 2006a; Meloni 2016; Lombardo 2008, 2011; Paul 1984, 1992). Eugenics

encompassed a diverse set of practices that included not only race-based segregations and the institutionalisation and (at worst) the killing of the ‘feeble-minded’, but also the development of public health and sexual hygiene programmes aimed at improving environmental conditions (Gyngell & Selgelid 2016), education programmes aimed at spreading eugenic ideas through education (in the UK); contests for the ‘fittest’ American family and campaigns for women’s right to abortion and access to contraception (Roberts 1997). It encompassed a wide range of policies such as the Immigration Restriction Act in the US and sterilisation laws in the US, Scandinavian and other countries, but also the legalisation of abortion in some of these countries (with the exception of for instance Norway) (Koch 2006a); it involved a variety of actors belonging to different political parties and embracing different ideologies (Kevles 1985; Meloni 2016; Paul 1984; Roberts 1997), from conservative defenders of the status quo to feminists campaigning for reproductive rights and from socialists and liberal democrats to racist right wingers. It was grounded in “epistemically pluralistic” theories of heredity, with both Lamarckian and Mendelian views influencing eugenic thinking (Gyngell & Selgelid 2016; Meloni 2016: 74; Schneider 1990), and both “soft” and “hard” theories of heredity justifying its principles (Meloni 2016: 65). It also involved the creation of different institutions such as the British Eugenics Society, the US Eugenics Record Office and the Mexican Eugenics Society. Contemporary historians (Adams 1990; Bashford 2010; Bashford & Levine 2010; Ekberg 2007; Kevles 1985; Koch 2006a; Lombardo 2008, 2011; Paul 1984, 1992) have set out not only to trace this history but also to show that eugenics was not confined geographically to Germany and North America and historically to the years immediately before, during and after World War II, but rather to a much more encompassing period of time and to diverse geographical areas: including Latin America, Central, Eastern and Northern Europe, and China. Differing views of the science of heredity (Gyngell & Selgelid 2016; Meloni 2016) and socio-political contexts (Roberts 1997) gave rise to a differing set of concerns, interventions and policies among geographical regions. For instance, as Roberts (1997) shows, in North America, eugenicists and feminists such as Margaret Sanger who advocated for birth control measures formed allegiances as the former “gave the birth control movement a national mission and the authority of

a reputable science” (Roberts 1997: 72), thereby inspiring policies in line with North America’s focus on controlling reproduction. Lamarckian and soft theories of heredity inspired eugenics programmes in Latin America and the ideas of British thinkers from the left (Gyngell & Selgelid 2016; Paul 1984, 2006), giving rise (in Latin America) to programmes aimed at “improving environmental conditions that influence transmissible (acquired) traits” (Gyngell & Selgelid 2016: 148).

Despite the differences among policies, actors, countries and periods of time, some of the features of 20<sup>th</sup> century eugenics common across time, space and political affiliations tend to emerge in contemporary discourses on these technologies and practices. These shared features of eugenics<sup>59</sup> are best identified in eugenics as an ideology (i.e. a set of ideas and beliefs) rather than in eugenics as a practice (i.e. laws, institutions and eugenic education). Eugenics as a practice was a rather heterogeneous phenomenon but it is possible to identify a core: one that it is shared over time, space and political affiliation<sup>60</sup>. This core was a concern with improving the quality of the population by preserving some human features considered beneficial for the collective and to avoid, or at least reduce, the transmission of negative features<sup>61</sup>. The etymological definition of eugenics and the definition formulated by Sir Francis Galton, the “father” of eugenics, capture these shared features. Etymologically, eugenics is composed of the Greek prefix ‘eu’ that translates as ‘good’ and the Greek word ‘genos’ that means ‘birth’ or ‘ancestry’. Galton’s original definition dates back to 1883, when he defined eugenics as:

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<sup>59</sup> For an interesting analysis of eugenic ideas throughout Western philosophical and political thought, see Häyry (2008).

<sup>60</sup> Concerning this, Meloni (2016) argues that “the varieties of eugenics in the first decades of the twentieth century were united less by direct politicization of a particular theory of heredity than by a *common ethos*, which crossed over the linguistic and aesthetic borders dividing eugenic approaches” ([emphasis in original] Meloni 2016: 66). The author identifies four main features of this “common ethos”, namely: radical biologism, utopian social engineering, “unlimited empowerment of scientific experts”, and the primacy of the race over the individual (Meloni 2016: 66-67).

<sup>61</sup> In this paper, I do not focus on or assess historical features of eugenics as my aim is to reflect on the relationship between past and present, and on how past eugenics is used in contemporary ethical debates. For detailed accounts of the history, see for instance: Adams 1990; Bashford and Levine 2010; Kevles 1985; Lombardo 2008, 2011.

## Who Should Come into Existence?

The science of improving stock – not only by judicious mating, but whatever tends to give the more suitable races or strains of blood a better chance of prevailing over the less suitable than they otherwise would have had.  
([emphasis added] Galton 1883)

These few features of eugenics as an ideology taken together represent the core of eugenics or, following Meloni (2016), the ‘common ethos’ of eugenics, but it is still difficult to draw lessons on which to base ethical assessments of reproductive technologies and practices (Bashford 2010; Paul 1998). When critics and proponents of reproductive technologies and practices warn that we should be wary of ‘going back’ to eugenics or that we should be very careful not to duplicate it, it is not always clear what they mean; as Paul (1998) puts it: “We’re warned against nothing in particular” (Paul 1998: 98).

Due to this complexity, and the emotional power that eugenics has, Wilkinson (2008), Camporesi (2014) and others working in the field of bioethics have suggested that reference to it ought to be abandoned, or at least significantly limited, in debates on reproductive technologies and practices. Their pleas, as well as contemporary efforts to distinguish between ‘good’ and ‘bad’ forms of eugenics, have not really changed current discourses on assisted reproduction as “the identification of a policy or practice as eugenic remains highly stigmatizing” (Paul 1998: 261) and references to eugenics in this context continue to abound.

So, historians are there and we need them. They have significantly helped to shed light on the history of eugenics and on the understanding of this phenomenon, on its complexity and multifaceted character. Depending on which aspects of this multifaceted history contemporary authors, policy-makers, journalists, activists and other members of the public look at, different lessons can be drawn and different strategies can be used to discuss, report, regulate, reject or defend reproductive technologies and practices. If eugenics is only depicted in terms of coercion or a quest for perfection (and assuming that both these practices are really ethically troubling), then what today’s technologies and practices need to avoid is to be driven by the latter and organised in terms of the former. If, instead, eugenics was really characterised by differing views of heredity, ideologies, objectives, policies and



practices then its lessons are much less straightforwardly derived (Buchanan et al. 2001). Despite this, I would regard knowing a comprehensive account of the history of eugenics as an ethical practice<sup>62</sup>. It is an ethical practice as on the one hand such knowledge can foster approaches, debates, interventions and policies that are not only mindful of what went wrong in the past, but also try to prevent (and perhaps redress) similar unfoldings. On the other, it can foster debates that are critical of and reflexive towards the social and political contexts in which they take shape and considerations of how both good and bad intentions can lead to undesirable states of affairs<sup>63</sup>.

What all the historical analyses have not managed to do is put to rest contemporary disagreement on what present technologies and practices count as eugenics and whether the similarity between past and present is a sufficient condition to settle the question of their ethical standing and value (Wilkinson & Garrard 2013). What *role* does the shadow of eugenics play within debates on reproductive technologies and practices? The reference to eugenics cuts across competing assessments of reproductive technologies and is used in different ways to create ethical boundaries between acceptable and unacceptable technologies, and their acceptable and unacceptable uses. Within these debates, recurrent questions are whether these technologies and practices amount to eugenics and/or whether they will lead us back to eugenics. However, if we aspire to move towards fruitful debates on the ethics of these technologies, I argue that our attention should be directed elsewhere rather than being channelled towards these questions. An alternative strategy to use in debates on the value and ethical standing of reproductive technologies is to look into the shadow of eugenics and uncover the relationship between past and present, how diverging interpretations of past practices inform our understanding of the present, and how they influence the contemporary disagreements concerning the ethics of

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<sup>62</sup> For an interesting discussion of the relationship between history and bioethics and of how these scholarships can be mutually beneficial, see Wilson (2013).

<sup>63</sup> Relatedly, Buchanan et al. (2001) concur that different accounts of the history have different implications for today's policy debates and that if today's genetics is "eugenics under a different name", then "we must achieve a clear understanding of the morality of both" (Buchanan et al. 2001: 40). See also Wikler (1999) and Gyngell and Selgelid (2016) on the lessons of eugenics.

reproductive technologies and practices. Looking into the shadow could, in other words, help those who participate in these debates to ask the right questions in order to collectively make progress both in the ethical assessment of these technologies and practices as well as in ethical debates on these technologies more generally.

Foucault, and Socrates before him, taught us that it is worth bearing in mind the importance of taxonomy and of reflecting on meanings as powerful analytical tools to interpret the complexities of reality. Looking into the meanings of eugenics is of interest as a conceptual tool to interpret the present. As Paul (1992) argued:

Eugenics is a word with nasty connotations but an indeterminate meaning. Indeed, it often reveals more about its user's attitudes than the policies, practices, intentions, or consequences labelled. ([emphasis added] Paul 1992: 665).

In the remainder of this paper, I will explore two questions: the role of the meanings and the uses of the word eugenics in debates on reproductive technologies and practices, and the role of assessments of the history of eugenics (and the lack thereof) in these debates. It is informed by an extensive review of publications that refer to eugenics to strengthen and ground arguments on the ethics of such technologies and practices.

### **2.3 What's in the Name Eugenics?**

In contemporary debates on the ethics of reproductive technologies and practices, the word eugenics is defined in a multiplicity of ways. The disagreement regarding the meaning of eugenics is not limited to what definition is the most appropriate and why, but rather it centres on “what counts as eugenics” (Wilkinson and Garrard 2013: 2), i.e. on which reproductive technologies and practices can be classified as eugenics, and whether this classification can settle the ethical questions that they raise. This section of the paper focuses on the role of the meanings, descriptions and definitions ascribed to eugenics in contemporary debates on reproductive technologies and practices.

One strategy to define the word ‘eugenics’ or to describe this phenomenon<sup>64</sup> within these debates would be to rely on a definition that is as descriptively accurate as possible, i.e. one that goes beyond the multiplicity of practices, ideologies and actors to capture the shared features of this multiplicity and that strives for neutrality in that it tries not to presuppose any explicit negative or implicit built-in value-judgment<sup>65</sup>. An example of such a definition of ‘eugenics’ would be: “the attempt to influence the genetic endowment of future generations”<sup>66</sup>. Many of the authors who refer to eugenics in debates on the ethics of reproductive technologies adopt this strategy and rely on this type of definition of eugenics<sup>67</sup>. For example, Anomaly (2014) describes eugenics as “any attempt to harness the power of reproduction to influence the genetic composition of future people” (Anomaly 2014: 179). Similarly, Glover (2006) argues that eugenics can be understood “broadly”<sup>68</sup> as “any decisions, including parental decisions, about what sort of child will be born” (Glover 2006:

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<sup>64</sup> Whether the word ‘eugenics’ should be referred to at all is discussed in the following section. I do not explicitly discuss the proposal of Agar (2008) and others who share his view of rehabilitating the term eugenics by adding the adjective ‘liberal’. While this use of the term eugenics differs from the uses of many other authors, those who speak about ‘liberal eugenics’ too have to decide which strategy among the ones described in this section they would adopt.

<sup>65</sup> A detailed discussion of the question of whether definitions can be entirely neutral, i.e. whether they can avoid *any* implicit or explicit value judgement is beyond the scope of this paper. I am personally sceptical with respect to the possibility of complete value-neutrality in definitions and descriptions of technologies and practices that are so fraught with emotive meanings, if only because definitions are formulated by ‘moral animals’ (Wright 1994): human beings with values and moral beliefs. For the present purpose, it is sufficient to say that whilst complete neutrality might be unattainable (Lakoff 2004; Stevenson 1937), the degree to which this can be attempted varies greatly, and one could opt for a definition that is as descriptively accurate as possible.

<sup>66</sup> This sentence captures the core of different definitions found in the literature which rely on the strategy described above, but the exact terminology might vary from publication to publication.

<sup>67</sup> What I would consider a subset of this group is made by authors who rely on a definition that captures shared features of eugenics (its core) and that is hence descriptively accurate, but which employs the word ‘improvement’ to describe attempts to intervene in and influence the genetic endowment of future generations. For instance, Selgelid (2014) defines eugenics “broadly” as: “a practice that aims to improve human lives by employing an understanding of heredity in the exertion of control over who gets born or who reproduces” (Selgelid 2014: 3) and Glover (2006) adopts the same strategy (see note below). Defining eugenics in terms of improvement entails remaining true to Galton’s original definition, which is arguably an instance of descriptive accuracy. Despite this, defining eugenics in terms of *improving* the gene pool (or with its terminological sibling ‘producing “fine children”’, Harris 1993: 178) may be interpreted as sneaking in a positive connotation and a built-in value judgement and hence failing the ‘strive for descriptive accuracy and neutrality’ test. I am indebted to César Palacios-González for bringing this to my attention.

<sup>68</sup> According to Glover (2006), eugenics can be also understood “narrowly” as: “social policies aimed at improving the gene pool” (Glover 2006: 28).

28). As I discuss in the next section, most of the authors that adopt this strategy (and most authors in general) do condemn eugenics, but they are also broadly in favour of reproductive technologies<sup>69</sup>.

A second strategy adopted by those who refer to eugenics in debates on reproductive technologies and practices is to rely on a definition or description of it that incorporates background ethical assumptions on the (negative) ethical standing of eugenics. For instance, Garland-Thompson (2012) describes “eugenic logic” as aiming to “eliminate disability and, by extension, disabled people from the world” (Garland-Thompson 2012: 340). Authors who oppose the use of CRISPR for germline editing and of MRTs associate eugenics with these practices (Brokowski et al. 2015; Darnovsky 2013). Similarly, in authors who condemn human enhancement, eugenics becomes synonymous with enhancement (and equally condemned) and the antonym of treatment (Habermas 2003; Sandel 2004a). Whether disability should be eliminated, or whether germline editing and human enhancement should be pursued, is a matter of contention in bioethics, as debates on the ethics of human enhancement<sup>70</sup>, on the ethics of screening technologies that allow to select against disability<sup>71</sup> and on the ethics of germline editing<sup>72</sup> show. My claim here is that these descriptions and definitions incorporate background ethical assumptions against germline editing, enhancement or against building a disability-free world and on the – related – ethical standing of eugenics. Hence, they opt for a different strategy to define and describe eugenics from the first group of authors described above<sup>73</sup>.

Therefore, even if authors tend to agree on the negative connotations of ‘eugenics’, they opt for different strategies to define this word. But which strategy should be

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<sup>69</sup> Other than the authors mentioned above, examples of authors in favour of new reproductive technologies that define eugenics in descriptively accurate terms are manifold. Just to mention a few of these authors: Agar (2008); Gyngell and Selgelid (2016); Robertson (2005).

<sup>70</sup> See for instance Buchanan (2011); Harris (2007); Sandel (2004); Savulescu and Bostrom (2009).

<sup>71</sup> See for instance Edwards (2004); Parens and Asch (2003); Shakespeare (2006).

<sup>72</sup> See for instance Gyngell et al. (2017); Cavaliere (2018a).

<sup>73</sup> I am very thankful to one of the anonymous reviewers for raising important questions about this section and for pressing me to improve it.

preferred? Should we opt for descriptive accuracy or for a definition that conveys a message that expresses one's own moral beliefs on the wrongness of eugenics? Or, again, should the word 'eugenics' be employed at all? As often in life, the answer to these questions depends on what one wants to achieve by using this word.

### 2.3.1 Descriptive Accuracy or Conveying a Message?

Many who refer to eugenics in debates on reproductive technologies either use a comparison with the past to show that such technologies are similar to eugenics and hence as morally problematic (the argument underlying the continuity view) or to show that these technologies are different from eugenics and hence not as morally problematic as eugenics was (the argument underlying the discontinuity view). In both types of arguments, the reference to eugenics is used to support one's position on the ethics of the reproductive technology or practice in question. It has, in other words, a normative role. Considering that both proponents and critics of reproductive technologies and practices agree on the negative connotations of eugenics, it may seem *prima facie* that it does not matter which definition they employ. They can say that eugenics is an attempt to improve the human gene pool or that it is an attempt to eliminate disabled people, and it would not matter for their arguments on contemporary technologies because that is where the moral disagreement lies. But words, metaphors and rhetoric matter greatly in these debates (O'Keefe et al. 2015; Ravitsky et al. 2015). As Blackburn (1998) argues: "Words typically nudge people, with more or less subtlety, towards attitudes to the things they pick out" (Blackburn 1998: 15), and they can redirect people's interests (Stevenson 1937). Employing the word 'eugenics' and a certain definition of it has normative implications: as Wilkinson (2008) shows and as others argue (Camporesi 2014; Gillon 1998; Paul 1998), the *use* of the word eugenics in contemporary debates on reproductive technologies has significant implications due to its emotive power and negative connotations.

Studies in moral psychology have provided evidence for how wording, context and order have *framing effects*<sup>74</sup>, namely they influence people's moral judgements on different matters (Haidt & Baron 1996; Haidt & Björklund 2007; Lakoff 2004; Petrinovich & O'Neill 1996; Sinnott-Armstrong 2007). A person's (moral) beliefs would be subjected to a word-type framing effect when "whether [or not] the person holds the belief depends on *which words are used to describe* what the belief is about" ([emphasis added] Sinnott-Armstrong 2007: 52) rather than on what the belief is actually about. So, a person's intuitions are subjected to framing effects if their moral beliefs regarding a given reproductive technology depend on the way the technology is described, on *which kind of words* are used to describe it rather than on the technology and its applications. Choosing one type of definition over another matters normatively because it can influence people's moral judgements concerning reproductive technologies and practices, and hence the decision to employ one type of definition or another is not per se neutral (Lakoff 2004).

Wilkinson (2008) argues that the word 'eugenics' should not be used in debates on the ethics of selective reproductive technologies due to its emotive power and negative connotations. According to this author, the word eugenics has the potential to unleash negative emotions that can "circumvent or neutralise people's critical-rational faculties" (Wilkinson 2008: 470) and cloud their judgement about the reproductive technology or practice being discussed<sup>75</sup>. Hence the word eugenics should not be brought up because it fails to respect the autonomy of those who engage with these debates<sup>76</sup> (Wilkinson 2008), because it is descriptively inaccurate

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<sup>74</sup> Word-framing effects have been studied most notably by Petrinovich and O' Neill (1996) and by Haidt and Björklund (2007). Petrinovich and O' Neill (1996) observed the effects on people's judgements on a given question being formulated in two different ways (one including the word 'kill' and the other including the word 'save') to describe two situations which would generate the same consequences. The consequences of the action entailed a certain number of people being killed and a certain number being saved in both situations, but participants were consistently much more likely to act when the word 'save' rather than when the word 'kill' was employed in the question. They judged the action more morally problematic (and hence they were not keen to act) when the word 'kill' appeared in the question. This is a typical example of a word-framing effect, one that works towards redirecting people's interests as in the case of eugenics and reproductive technologies and practices.

<sup>75</sup> Wilkinson (2008) discusses this phenomenon in the context of PGD.

<sup>76</sup> According to Wilkinson (2008), the word 'eugenics' should be avoided regardless of one's own moral beliefs on reproductive technologies and practices as "there are some ways of communicating

and because it does not add anything in terms of conceptual clarity (Camporesi 2014; Gillon 1998). I am sympathetic to such analyses and certainly in favour of conceptual clarity and of avoiding misleading and factually wrong<sup>77</sup> references to historical events. ‘Eugenics’ is indeed used as the *‘reductio ad Hitlerum’* described by Strauss (1953) whereby a person or a practice becomes guilty by virtue of their association with the Nazis (Strauss 1953). The comparison between reproductive technologies and historical eugenics is often used to condemn by association these technologies.

Despite this, it seems odd that the best strategy to protect people’s rational capacities is to deliberately avoid the use of a word, even a heavily emotively-loaded word. There are different reasons why the word eugenics features in association with reproductive technologies: it may be that the user believes that these technologies are similar to eugenics or at least that they are comparable to it in meaningful ways; or it may be that the user is motivated by eugenics’ persuasive power and its potential to elicit negative assessments of reproductive technologies. In the former case, what matters is whether the user is factually wrong or not; in the latter, it matters what rules of moral argumentation are set in debates on reproductive technologies and practices.

As the stakes are high (we are talking about the ethical assessment of reproductive technologies and practices), it is reasonable to state that one should be careful about how to use the word ‘eugenics’ and how one chooses to define it. Hence I would suggest that contrary to what Wilkinson (2008) and others argue we should aim to adopt a reflective approach to the use of the word eugenics rather than to make it taboo. We should aim for conceptual clarity, for definitions that are as descriptively accurate as possible, that fairly represent what eugenics encompassed, and that are informed by the work of historians of eugenics. A description-oriented definition of

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that, without lying or misleading, fail to respect people’s autonomy: methods of communication that circumvent or neutralise people’s critical-rational faculties” (Wilkinson 2008: 470). Following this view, which Wilkinson considers “non-partisan” and defines as “the Autonomy argument” against using the word eugenics, *both* those in favour of and against reproductive technologies have an interest in not referring to the word ‘eugenics’ as both camps should aim for a “rational” debate.

<sup>77</sup> With the term ‘factually wrong’, I mean references to the past that do not describe documented events of the past or that deny that certain documented events have taken place.

eugenics would allow us to start with a common ground to discuss both the history of eugenics and the ethics of reproductive technologies.

There are different reasons why those who participate in debates on the ethics of reproductive technologies should, where possible, avoid definitions of eugenics which are fraught with negative connotations and that conflate descriptive and evaluative elements. These definitions serve the normative goal of critics of reproductive technologies (i.e. elicit negative judgements of these technologies), but do not improve the ethical debate insofar as they turn the attention to whether these technologies are eugenics rather than on relevant moral aspects of these technologies. They pre-determine the moral questions and hence shape the debate by deciding beforehand which aspects should be given attention and which are irrelevant (Jasanoff et al. 2015). They pre-determine what ethical questions should be discussed and what direction the ethical debate should take, thereby excluding views that do not fit within the pre-established framework. They add ethical complexity to already complex questions, and they do not provide those participating in the debate with a way to make sense of this complexity. Regardless of one's normative goal, then, intellectual honesty would call for definitions, meanings and uses of the word 'eugenics' which are as descriptively accurate as possible. Only in this way can we really assess whether the comparison with past and present is warranted and make steps forward in the ethical debate on reproductive technologies.

### 2.4 The Discontinuity and Continuity Views

Let me take a moment to recall the form taken by two commonly used arguments within debates on the ethics of reproductive technologies and practices which involve references to eugenics. The first set of arguments that stress the discontinuity between past and present goes something like this:

1. x, y and z are morally wrong acts;
2. eugenic practices entailed x, y, and z;

∴ old eugenic practices are morally wrong.



3. a (a reproductive technology or practice) does not entail carrying out x, y, and z;

∴ other things being equal, a is not morally wrong.

The opposing set of arguments, which stress elements of continuity between past and present, runs something like this:

1. x, y, and z are morally wrong acts;
2. eugenic practices entailed x, y, and z;

∴ old eugenic practices are morally wrong.

3. a (a reproductive technology or practice) entails carrying out x, y, and z

∴ other things being equal, a is morally wrong.

Throughout the rest of the paper, I refer to these two views as the discontinuity view and the continuity view of past and present. My argument is that the understanding of the history of eugenics and the features of the history upon which one focuses are deeply interlinked with the claims that one makes about the ethics of reproductive technologies.

#### **2.4.1 The Discontinuity View**

Those who hold the discontinuity view condemn characteristics of eugenics concerning its scientific foundations. More specifically, they hold that eugenics was informed by a limited knowledge of the science of heredity (Epstein 2003; Glover 2006), that it did not meet appropriate ethical and scientific standards of research (Appel 2012; Tong 2013), and that it mistakenly relied on the belief that social, behavioural and ethnic features could be flattened and reduced to mere biological dimensions (Buchanan et al. 2001; Scott 2006). A second problematic feature of eugenics is identified in its underlying racist and discriminatory beliefs, and in the policies that these beliefs inspired (Agar 2008; Buchanan et al. 2001; Robertson 2005; Savulescu & Kahane 2009; Scott 2006). The authors defending this view largely focus their attention on North American immigration policies designed to restrict incomers from certain ethnic groups (i.e. Southern and Eastern Europe), on

American sterilisation policies that targeted people with physical and mental disabilities and members of lower socio-economical classes (Appel 2012; Crossley & Shepherd 2003), and on Nazi eugenics aimed at creating a ‘master race’ through the elimination of people with disabilities (Blackford 2005; Glover 2006; Walker 2010).

In addition to bad science and discriminatory beliefs, coercion, in debates on reproductive technologies and practices, becomes the capital sin of past eugenics<sup>78</sup> (Agar 2008; Bruni et al. 2012; Caplan et al. 1999; Crossley & Shepherd 2003; Glover 2006; Robertson 2005; Santosuosso et al. 2007; Savulescu & Kahane 2009). While agreeing that coercion was one of the most problematic elements of eugenics, authors discussing this feature focus on slightly different features of it: some criticise state interference in the realm of reproduction and the denial of what today is defined as ‘procreative liberty’<sup>79</sup> (Robertson 2005). Others mainly address the question of exercising control over biological features of the population (Bouffard et al. 2009; Dolgin 2004), whereas another group sees in coercion a denial of the respect for individuals’ bodily integrity (Appel 2012; Santosuosso et al. 2007). A final reason why eugenics is perceived as despicable is that its policies and aims were oriented towards the improvement of the wellbeing of the population rather than the good of the individuals (Fenton 2006; Glover 2006; Robertson 2005; Savulescu 2005; Scott 2006). In all these references to the past, despite some internal differences concerning the most contemptible elements of eugenics, old eugenics is unanimously condemned. What varies is the weight that should be assigned to ‘x, y, z’, i.e. to each of the features of eugenics on which scholars participating in debates on the ethics of reproductive technologies focus. The discontinuity view underlines the idea that if reproductive technologies and practices do not entail ‘x, y, z’, namely coercion, bad science, discriminatory beliefs and a precedence of population-concerns over individual-concerns, *then* they are not ethically troubling in the same way as eugenics.

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<sup>78</sup> This is also shown by the number of publications which address the question of coercion. In spite of this, most of the authors do not define what they mean by coercion and which features make eugenic policies and practices coercive.

<sup>79</sup> Or, alternatively: “reproductive freedom” (Brock 2005; Harris 1992; Cavaliere & Harris 2018).

Authors relying on the discontinuity view to support their disanalogy between the past and present argument make slightly different claims about the present and about the relationship between past and present. For instance, some argue that past eugenics and reproductive technologies do not share any significant feature (Bourne et al. 2012; Savulescu & Kahane 2009). These authors argue that reproductive technologies are guided by values and inspired by moral beliefs that have nothing to do with those of eugenics: while eugenics was discriminatory and exclusionist, reproductive technologies are value-neutral with respect to race, gender and class, and oriented towards the welfare of the future child or designed to enhance autonomous decision-making (Glover 2006; Harris 2007; Savulescu & Kahane 2009; Robertson 2005). In their accounts, past and present differ in terms of both the underpinning values and the means employed: while eugenics was coercive, violent, and entailed forced sterilisations and mass killings, today's reproductive technologies are freely chosen, do not entail gruesome methods and are available to those who wish to use them (Appel 2012; Bourne et al. 2012; Robertson 2005; Savulescu & Kahane 2009).

Other authors allow that although these technologies share features with past eugenics, they are still free of the characteristics that made eugenics morally wrong (Agar 2008; Camporesi 2014; Fenton 2006; Harris 1993; Scott 2006; Wilkinson 2010). For instance, Wilkinson (2010) reflects on the question of whether “the very idea of ‘genetic improvement’ is a mistake” (Wilkinson 2010: 159) and concludes that the answer to that question, once we add some qualifications (which he offers in his book), is negative:

There have been many versions of ‘eugenics’ that have incorporated dangerously flawed ideological and pseudo-scientific beliefs, such as Nazi racial ‘science’. However, there is no need to assume that all attempts to improve the ‘gene pool’ will be similarly flawed [...]. So perhaps (for example) improving the gene pool in ways that improve future public health would be morally acceptable (and even desirable). ([emphasis added] Wilkinson 2010: 166)

Similarly, Harris (1993), in addressing the question of whether gene therapy should be considered a form of eugenics, argues that if one relies on an understanding of eugenics akin to the understanding that its father, Francis Galton, had, then the

answer is positive. Eugenics and gene therapy have a common aim: they both seek to produce “fine children” (Harris 1993), an aim that, in the eyes of the author, is considered worthwhile. This aim is worth pursuing both in the case of attempting to “remove or repair dysfunction” and in the case of “measures designed to enhance function”<sup>80</sup> (Harris 1993). These authors (and other sharing their view such as Agar 2008) rely on a broader understanding of eugenics as the attempt to improve the gene pool of the population and argue that what was problematic in the past was *how* eugenicists tried to achieve human improvement, i.e. the relying on coercive and violent measures, rather than on the aim of eugenics and its underpinning values per se.

### 2.4.2 The Continuity View

The authors who defend the continuity view broadly agree with those defending the discontinuity view with respects to the condemnable features of eugenics. For instance, some scholars criticise its faulty scientific foundations and the quest for singling out biological components of social characteristics (Jeffreys 2012); others focus on the coercive character of eugenics’ policies and practices (Epstein 2003), their incorporation into the political agenda (Hampton 2005; Roberts 2009), their violation of bodily integrity and of reproductive freedom (Epstein 2003; Roberts 1997). Despite the similarities between those defending the discontinuity and the continuity view in terms of the condemned features of eugenics, the degree to which these features are considered problematic and the moral weight given to each feature differ substantially. Contrary to those who defend the discontinuity view, most of the authors defending the continuity view do not see in coercion and state-driven practices the capital sins of eugenics. They instead focus on eugenics’ discriminatory attitudes, on its morally wrong underpinning values, on the policies that were designed following these values, and on the effects on minorities and vulnerable groups of these attitudes, values and policies (Garland-Thompson 2012; Hampton

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<sup>80</sup> Harris here relies on a critique of the existence of significant moral differences between therapy and enhancement. I will not enter in this debate here, but Harris, among others, does so throughout his work (Harris 1992, 2007).

2005; MacKellar & Bechtel 2014; Roberts 1997, 2009; Rosen 2003; Sparrow 2011a). They also stress eugenics' 'unhealthy' preoccupation with perfection (Bashford 2010), and argue that eugenic practices of the past were ultimately driven by the purpose of perfecting the population. This aim is considered problematic not because – as the defenders of the discontinuity view would argue – their efforts were directed at the population rather than at the individual, but because of the immorality of the aim itself (MacKellar & Bechtel 2014; Rosen 2003; Sandel 2004a).

Commentators agree on the wrongness of most practices within 20<sup>th</sup> century eugenics, on the aberrant means used to pursue its aims and on the need to avoid repeating these mistakes, but they draw different lessons from these analyses, and they develop competing assessments of contemporary reproductive technologies and practices. The reason for this, I argue, is that their views diverge on the underpinning values of eugenics (such as the desirability of improving the human gene pool) and to the weight that is given to each condemned feature of 20<sup>th</sup> century eugenics. The moral disagreement on the present has roots in a disagreement about the past<sup>81</sup>, and past and present are profoundly interlinked in these accounts.

Authors supporting the continuity view present a number of reasons to draw attention to the meaningful similarities between contemporary technologies and practices, and features of 20<sup>th</sup> century eugenics. For instance, some stress that the (cumulative) effects of these practices match some of the effects sought by eugenicists or some of the effects eugenic policies sought to engender. Screening technologies such as PGD and PND, but also new reproductive technologies such as MRTs, will contribute to a decrease in the number of disabled people and to members of ethnic minorities (Hampton 2005; Garland-Thompson 2012; de Melo-Martín 2017a; Roberts 2009). This decrease is considered by these commentators to be not only ethically troubling in itself, but also for consequentialist reasons, i.e. for the effects that it will have on these groups. The fear is that members of certain ethnic groups (Roberts 1997, 2015; Russell 2010); women (de Melo-Martín 2017a;

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<sup>81</sup> As argued above, the past must be known in all its nuances and complexities in order to assess it from an ethical point of view and for it to be of any interest in present debates.

Epstein 2003); and disabled people (Garland-Thompson 2012) will be increasingly stigmatised, as they were in the past, and publicly funded services available to them will be reduced (Garland-Thomson 2012; Scully 2008; Sparrow 2008, 2011b).

While authors defending the continuity view do not see in coercion one of the chief wrongs of eugenics, they still condemn it and argue that some elements of coercion survive in contemporary reproductive technologies and practices. Unlike supporters of the discontinuity view, these authors stress that the alleged diminished intervention of the state in matters of procreation is either a misrepresentation of the present situation or a sign that coercion is understood in an unduly narrow sense. For instance, Sparrow (2008) argues that the fact that certain screening technologies are “made available” signals the continuity of state interventions in matters of procreation. Not only that, but according to other critics of reproductive technologies and practices that refer to eugenics, coercion is an element of today’s technologies and practices even if the state does not have an active role in promoting them (Mehlman 2011; Mittra 2007; Sparrow 2011b). Following these authors, other than from direct state interventions, coercion may result from the pressure to use reproductive and screening technologies exercised by healthcare professionals (Ekberg 2007; Koch 2006b), scientists (Darnovsky 2004; Ekberg 2007), and bioethicists (Koch 2006b). Other than coercion, what troubles defenders of the continuity view about eugenics is the quest for perfection that it entailed. In their view, this quest is embodied by reproductive technologies and practices (Sandel 2004a).

## **2.5 Learning and Moving Forward**

I started this paper by arguing that historians have reconstructed the unfolding of eugenics and brought to light the multiplicity of themes, policies, actors and values which it encompassed. Learning from history in order not to repeat the mistakes of the past is a noble, and some would argue a necessary, endeavour. But to learn from history, history must be known. Partial or inexistent historical accounts make it extremely difficult to learn from the past and, as Bashford (2010) puts it:

Selective understandings of the history of eugenics may seriously mislead contemporary efforts to regulate reproductive and genetic technologies, and be a questionable basis for policy decisions. (Bashford 2010)

As I showed in the previous sections, despite unanimously condemning eugenics, defenders of the discontinuity and continuity views focus their attention on slightly different ethically troubling features of the past. While defenders of the discontinuity view see coercion and population-wide eugenic policies and practices as the most problematic feature of 20<sup>th</sup> century eugenics, defenders of the continuity view see the callous attitudes towards disabled people and other minorities, and the drive towards improving the gene pool of the population as the most despicable feature of eugenics. These differing ethical assessments of the past are linked with differing ethical assessments of the present: defenders of the discontinuity view stress how reproductive technologies and practices both promote and protect reproductive freedom and individual welfare (as opposed to population-wide approaches) and individual autonomy (as opposed to coercion). They see in the promotion and protection of these values the most salient characteristics of reproductive technologies and practices, and the reasons why they should be welcomed. On the contrary, defenders of the continuity view stress how reproductive technologies and practices both embody and play a role in the persistence of the drive towards perfecting the population and of the discriminatory attitudes towards women, disabled and black people, and the reasons why they should be condemned. They see in this condemnation and problematisation of these technologies and practices a means to promote different values. These differing ethical assessments of the past can also explain why proponents of the discontinuity view often dismiss concerns about the present expressed by those who support the continuity view. They dismiss them as signals of conservative attitudes towards new reproductive technologies and practices and of a poor understanding of today's effects and uses of these technologies and practices. However, in reality, the two groups condemn and justify different features of the past and of the present.

Historians and critical theorists have warned of the risk of focusing excessively on the coercive character of eugenics whilst ignoring the patterns of coercion and discrimination present in reproductive technologies and practices (Bashford 2010;

Ekberg 2007; Roberts 1997). On the one hand, eugenicists advocated voluntary forms of eugenics; on the other, social pressure, discriminatory attitudes and barriers to fully exercise and to have respected one's reproductive freedom may be (in different ways) features of today's reproductive technologies too (Bashford 2010; Koch 2006a; Paul 1992). The discontinuity view's underlying arguments draw a line between historical eugenics as coercive and reproductive technologies as freely chosen by autonomous individuals, but the reality is much more blurred than advocates of such technologies make it out to be. At the same time, authors focusing on the callous attitudes towards disabled people, women and ethnic minorities, and on persisting biases and forms of discrimination enacted within and by reproductive technologies and practices may risk overlooking significant differences from the past in terms of the political and social context in which reproductive technologies and practices are developed. While it is undoubtedly true that despicable attitudes still exist and that they should be resisted, efforts and steps towards fostering respect for these groups, to guarantee them public assistance and to develop means for greater integration, are being made. Additionally, empirical data have shown that parents who make use of reproductive technologies are not driven by a quest towards perfection or by discriminatory beliefs (Franklin & Roberts 2006; Kerr 2004).

Once history – in all its complexities, nuances, peculiarities – is known, we can learn from it. We can start with a common ground that avoids misleading assessments and misleading conclusions. Despite this, such knowledge about history cannot solve is the moral disagreement concerning what underpinning values are worth pursuing and what others are worth dismissing. It cannot answer, in other words, the question of which aims and values reproductive technologies and practices should serve. History can tell us that coercion was not the only nor the most distinctive feature of eugenics, but it cannot tell us whether trying to improve the gene pool of the population and trying to increase the number of babies born without disabilities are worthy aims (as most defenders of reproductive technologies argue). Similarly, it can tell us about eugenic policies and how those policies contributed to an increased stigmatisation of disabled people and of the perceived need to wipe them out, but what it cannot tell us is whether allowing gene editing technologies will lead



prospective parents to select blond blue-eyed babies and whether this is something that should be opposed.

For these reasons, while it is important to learn *about* the history of eugenics and learn *from* the history of eugenics, this is probably all that eugenics should contribute to contemporary debates on reproductive technologies. Mainly focusing on eugenics and on analogies/disanalogs between past and present risk jeopardising contemporary debates on the ethics of reproductive technologies and shifting the focus away from relevant questions about the value of reproductive technologies and practices.

## **2.6 Conclusions: Looking into the Shadow**

In this paper, I have discussed how the word eugenics and the history of eugenics are used in debates on the ethics of reproductive technologies and practices. I have showed that some commentators employ definitions of ‘eugenics’ which are descriptively accurate while others opt for definitions which immediately bring to the fore the negative connotations of this phenomenon. I have argued that, when possible, the former type of definition should be preferred over the latter. I then moved on from a discussion of the uses of the word to the uses of the history of eugenics and showed how authors who focus on certain problematic characteristics of the past tend to have views on contemporary reproductive technologies and practices that are symmetric with, and a response to, these characteristics.

The shadow of eugenics extends to contemporary reproductive technologies and practices and it is a legacy that will probably be hard to eradicate, and it might not even be desirable to do so. Scholars who participate in debates on these technologies should learn about the historical unfolding of eugenics in order to avoid repeating the same mistakes that were committed in the past.

## 2.7 Declaration

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### 3 PAPER 2: A Path Through the (Moral) Morass: Genome Editing, Reproduction and Broad Conversations

Paper 2 is a single-authored chapter published in an edited volume titled *Between Moral Hazard and Legal Uncertainty. Ethical, Legal and Societal Challenges of Human Genome Editing* (edited by Matthias Braun, Hannah Schickl and Peter Dabrock).

The version of this chapter enclosed in Appendix 2 is the chapter's published version.

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#### 3.1 Abstract

In this chapter, I discuss the possibility of using genome editing technologies in the context of assisted reproduction. I present the most prominent arguments in favour of and against this use of genome editing technologies, and explore two strategies used in bioethics in the event of moral disagreement to analyse the questions at hand and to develop morally sound policies. These strategies are: the clarification of the facts regarding a new technology and the formulation of the best philosophical argument. I contend that both approaches are theoretically flawed and might result in states of affairs that fail to promote peoples' well-being. I then argue that we should focus instead on finding at least some common ground in order to move forward in the debate on genome editing, building a regulatory framework that lightens "the burden of human existence" (Harris 2016a), whilst still accommodating opposing views as much as possible. Furthermore, I argue that insights from moral psychology and democratic governance can assist us in these challenges.

**Keywords:** Assisted reproduction | Deliberative democracy | Moral judgment | Pluralism | Safety

### 3.2 Genetic Technologies and (Moral) Disagreement

New reproductive technologies and screening technologies allow couples who are at risk of transmitting genetic diseases to their offspring to reduce the risk of transmission while still being able to have genetically related (or partially genetically related) offspring. Most of these technologies and their applications are controversial. There is no consensus regarding the legitimacy of their use and whether or not they are a morally acceptable means in the pursuit of parenthood projects. Some people oppose pre-natal and pre-implantation screening technologies because of their discriminatory nature and because they express – or strengthen – negative attitudes towards people with disabilities (Parens & Asch 2003). Others contest that these technologies could bring about increased inequality as well as sexist and racist attitudes (Roberts 1997). Others criticise them for violating human dignity and for tampering with human nature (Kass 1997), while still others are more concerned with the reinforcement of certain beliefs about the importance of genetic parenthood and the traditional family (de Melo-Martín 2017a). If there were agreement regarding these criticisms, bioethicists would be out of a job (together with the scientists developing them, the healthcare professionals working in the fertility clinics, and the policy-makers regulating their use).

Fortunately (I am a bioethicist and I do not want to be out of a job), these technologies are also welcomed by many, since they allow people to pursue their preferred life plans, to have children that are genetically related to them, and who are healthier than they otherwise would have been. They, as Harris (2016a) puts it, help “lighten the burden of human existence” (Harris 2016a: 16). In this chapter, I focus on genome editing technologies and on their applications, in the context of assisted reproduction, for the correction of genetic abnormalities in embryos created with in vitro fertilization (IVF). I discuss this possibility, presenting some insights from the literature on moral psychology which can be considered a starting point for a debate on the challenges of institutional design.

Gene editing technologies have been around for over a decade now (Nuffield Council on Bioethics 2016). Despite this fact, one new gene editing technique in particular sparked a heated debate early in 2015, and to date, the debate has yet to

be settled. Calls for a moratorium on the use of this particular technique as well as for international bans and joint efforts to prevent its applications in the clinic abound (Baylis 2017b, 2017c; Baltimore et al. 2015; Lanphier et al. 2015; UNESCO IBC 2017). The technique in question is CRISPR (Clustered regularly interspaced short palindromic repeat), an RNA-guided tool that makes use of a naturally occurring defence mechanism employed by bacteria to avoid harmful infections caused by pathogenic organisms (e.g. viruses). The RNA tool (CRISPR) functions as a guide for other systems (Cas9, CPF1 and others) to target specific parts of the genome, which are subsequently cut by the Cas proteins. These cut strands can be exploited to modify the nucleotide sequence of DNA and to insert DNA sequences at the cut site. The application of this technique to human embryos and human gametes (i.e., oocytes and sperm cells) has been widely criticised for a number of reasons, but chiefly for its potential to introduce inheritable changes in the human genome. The question of consensus has catalysed the attention of many scientists and ethicists and has transformed CRISPR into one of the most discussed technologies of the past years (Brokowski et al. 2015; Lander 2015; Lanphier et al. 2015). The technique's precision, effectiveness and relatively limited cost, together with its potential to edit the human germline in a targeted manner, which elevates it above many other genome editing technologies, have led ethicists, scientists, reporters and members of the public to call for international solutions to what is perceived to be an international challenge (Baylis 2017b, 2017c; National Academies of Sciences, Engineering and Medicine 2015).

### **3.3 Broadening the Conversation**

One of the proponents of these international solutions and broad conversations is Baylis (2017b, 2017c), who writes:

Why struggle? Because although all humans have a common interest in the human genome, much work is needed to identify other common interests that might rightfully guide policy deliberations. Hence, there is merit in [...] embracing the challenge of seeking broad societal consensus on this ethically controversial issue. (Baylis 2017b: 3)

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Elsewhere, she continues defending the view that citizens should work towards broad societal consensus, because:

We are talking about nothing less than the future of the human species. No decisions about the modification of the germline should be made without broad societal consultation. (Baylis 2017c)

Similarly, the statement produced after the International Summit on Human Gene Editing in December 2015 states that:

It would be irresponsible to proceed with any clinical use of germline editing unless and until [...] there is broad societal consensus about the appropriateness of the proposed application. (National Academies of Sciences, Engineering and Medicine 2015)

The problem with international and broad solutions is that we, members of *Homo sapiens*, often disagree. We disagree about everything: from climate change to national health services, from redistribution of income and wealth to genetically modified organisms, from vaccinations to sustainable diets. Our disagreements span from the evaluation of scientific methods to ethics and policy. They occur between and within countries, depending on personal and collective values, beliefs and practices, and – importantly – political and cultural frames (Jasanoff 2011). We tend to see the world through “different moral lenses” when it comes to values we hold dear (Greene 2014: 68).

In the face of all these disagreements, we can adopt different strategies, including throwing in the towel and not attempting to build such broad social consensus, or forcing the view held by the majority on the minority. Broad societal consensus might be unachievable and perhaps even undesirable. It may be unachievable due to our differing moral world-views and our tribal tendencies to defend them (Greene 2014; Haidt 2012). It may also be undesirable inasmuch as it requires those participating in the debate on the ethics of genome editing to relinquish at least some of these moral views, or to restrict them to the private sphere and not bring them to the fore/um. It requires doing ethics, not inside the cave and among philosophers and ethics experts, but in the public square, where different moral views and “competing rationalities” coexist (Häyry 2010: 48). This is what commitment to a

deliberative conception of democracy would encourage us to do (Cohen 2003; Gutmann & Thompson 2009). It would encourage us to engage in a process of public reasoning, where we collectively discuss contrasting moral views and engage in “visions of progress that are collectively defined, drawing on the full richness of democratic imagination” (Jasanoff et al. 2015: 48). As we move from bioethics journals to institutional design and public policy, we need to be able to create an inclusive space for discussion of the ethical, political and social challenges raised by genome editing. We need to be able to develop policies that take account of these challenges and the competing moral views and values that underpin them.

For this reason, I side with Baylis’ general intuition and with her plea for broad conversations on genome editing<sup>82</sup>. My view on the importance of an inclusive dialogue is motivated by a commitment to a deliberative understanding of democratic decision making, but also, as Peter Mills (2017) puts it, because we are in the field of “geo-ethics”, where what matters are the:

[I]nteractions of formal institutions, organisations and polities that recognise the potential for the spatiotemporal diffusion of genome editing technologies across political geographies and legal jurisdictions. (Mills 2017: 69)

It is within and between such diverse and broad contexts, within and between ‘different social and cultural realities’, that these technologies will be in play (Mills 2017).

What then should we do with genome editing? Should we take such competing moral views into account? Should we take all of them into consideration, or are there some views which should not be accepted in the public arena? Despite people’s tendency to favour the moral views that resonate with their own and to discard opposing views as flawed, immoral, unacceptable etc., when it comes to developing policies, there are very good reasons to try to find certain overlaps among differing

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<sup>82</sup> I am not convinced by Baylis’ idea of ‘broad societal consensus’. I see the rhetorical appeal of such a proposal, but I think that aiming for “broad conversations” and trying to resolve, even partially, the disagreement is a) more feasible and b) more desirable. My argument then hinges more on the idea of ‘partially overcoming the disagreement’, and trying to have ‘broad conversations’ (i.e. as inclusive as possible), than on Baylis’ idea of ‘broad societal consensus’.

‘moral tribes’ (Greene 2014). I return to these questions (and to a tentative response to them) in section 3. Before that, I briefly explain how genome editing could be used in the context of assisted reproduction and then delineate some of the arguments put forward against and in favour of this possibility.

### 3.4 Reproductive Options and Genome Editing as a New Possibility

Couples who do not rely on assisted reproduction, and who wish to reduce the risk of transmitting a genetic mutation to their offspring, could refrain from having genetically related children and turn to adoption<sup>83</sup>. Alternatively, prospective parents can rely on reproductive technologies, such as IVF with gamete donations (third-party reproduction), or screening technologies, such as pre-implantation genetic diagnosis (PGD), to decrease the risk of having children with the genetic mutation they carry. In some cases, PGD is not an option as none of the embryos created through IVF is free from the undesirable genetic mutation (Vassena et al. 2016). For instance, when one of the prospective parents is homozygous for a dominant genetic disorder, the risk of transmission to offspring is as high as 100%, and hence no mutation-free embryos can be obtained. When prospective parents are both heterozygous for a dominant genetic disorder, the risk of transmission is as high as 75%, making the chances of finding mutation-free embryos significantly low. Another case where PGD is not effective is when both parents are homozygous for a recessive genetic disorder (the risk of transmission to offspring is as high as 100%), meaning that they both carry two variants of the disease-causing gene (Nuffield Council on Bioethics 2016; Vassena et al. 2016). In such cases, genome editing could be employed directly on the embryos created with IVF to ‘correct’ mutations which potentially lead to monogenic diseases, and to correct mitochondrial DNA

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<sup>83</sup> I do not discuss this option in this chapter. Rather, I focus on the available options granted by existing and new assisted reproductive technologies. For a discussion of adoption, and why it is a morally preferable alternative to assisted reproduction, see for instance: de Melo-Martín (2017a) and Rulli (2016b).



mutations which lead to mitochondrial DNA diseases (Vassena et al. 2016)<sup>84</sup>. Using genome editing on early embryos could give to prospective parents, who are at risk of transmitting genetic mutations to their offspring, a chance at having children who are genetically related to them, while decreasing the risk of transmitting the parents' genetic mutations<sup>85</sup>.

### 3.4.1 Genome Editing: Proponents and Critics

Research on human embryos with CRISPR technology is still in an early stage and only a few experiments have been carried out thus far (Vassena et al. 2016). Despite this, the possibility of allowing clinical research has been discussed recently (Chan et al. 2015; Gyngell et al. 2017; National Academies of Sciences, Engineering and Medicine 2017; Reyes & Lanner 2017; Vassena et al. 2016). Critics advance two related, precautionary reasons against clinical applications of genome editing on human embryos or gamete cells: that these applications would lead to germline modifications and that assessing the safety of these applications would be either problematic or impossible. Those who worry about germline modifications view them akin to an (ethical and biological) 'line that should not be crossed' (Collins 2015; UNESCO IBC 2017)<sup>86</sup>. The worry about germline modifications expresses two underlying types of concern: deontological concerns about the intrinsic wrongness of introducing inheritable changes in the human genome, and consequentialist concerns about unforeseen effects for future generations, technology's running astray and the possible resurgence of eugenics (Lanphier et al. 2015; MacKellar 2017; Pollack 2015).

The first type of concern, which I refer to as 'deontological', implies a principled position against germline modifications, regardless of the morality of the outcomes

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<sup>84</sup> Currently, the U.K. is the only country where mitochondrial DNA replacement techniques are allowed and regulated. Such techniques represent the only existing method for couples in which one member is affected by a mitochondrial condition to have genetically related children.

<sup>85</sup> I do not discuss alternative forms of procreation, that do not entail genetic parenthood, in this chapter. I discuss the ethics of using new technologies to have genetically related, healthy babies and the broader societal implications of such decisions in Cavaliere (2018a).

<sup>86</sup> For a discussion of this claim, see Camporesi & Cavaliere (2016).

of such practices<sup>87</sup>. For instance, the 2017 statement of the UNESCO International Bioethics Committee (IBC) reads:

Interventions on the human genome should be admitted only for preventive, diagnostic or therapeutic reasons and without enacting modifications for descendants. The alternative would jeopardize the inherent and therefore equal dignity of all human beings and renew eugenics. (UNESCO IBC 2017)

Sometimes this principled objection echoes concerns regarding the intrinsic and inviolable value of human dignity and of what is ‘naturally’ produced (Kass 1997; Sandel 2007), as opposed to what is technically designed.

The second type of concern, which I define as ‘consequentialist’ due to its focus on the state of affairs possibly effected by genome editing, encompasses objections related principally to the unforeseen effects of modifying the human germline, and the impossibility of thoroughly assessing the safety of these technologies (Baylis 2017b; Lanphier and Urnov 2015). At the current stage, safety is indeed an issue, and the efficiency of genome editing on embryos is still low, with mosaicism in edited embryos (i.e., edited embryos showed a mixture of edited and unedited cells) being the main known drawback of these technologies (Vassena et al. 2016).

### 3.4.2 The Case for Genome Editing

Those who argue in favour of the use of genome editing in the context of assisted reproduction agree that safety concerns must be thoroughly assessed before proceeding. Indeed, even the most vocal proponents of genome editing, and new reproductive technologies more generally, defend their clinical uses via the important caveat of assessing the risks that these technologies may pose to future children<sup>88</sup> (and the children of these children) (Chan et al. 2015; Harris 2016a; Savulescu et al. 2015). For instance, Savulescu and colleagues (2015) argue that there

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<sup>87</sup> It also encompasses the objection to so-called enhancing uses of technologies, i.e., uses that are not aimed at treating genetic conditions, but at changing non-diseased traits (such as height, eye-colour or intelligence).

<sup>88</sup> A position that represents a *de facto* argument in favour of gene editing research (Savulescu et al. 2015).

is a moral imperative to continue gene editing research on human embryos in order to reduce off-target mutations and other safety issues, since “[a]dvanced and precise gene editing techniques could reduce the global burden of genetic disease and potentially benefit millions worldwide” (Savulescu et al. 2015: 476). Gyngell and colleagues (2017) focus on the clinical application of genome editing (especially in the context of assisted reproduction) and state that there is a “significant medical case for pursuing GGE [germline gene editing]” to prevent the occurrence of genetic diseases in future generations (Gyngell et al. 2017: 499). Two sets of arguments have been advanced in favour of using genome editing technologies on embryos to correct genetic abnormalities, provided that safety concerns are properly addressed (Gyngell et al. 2017; Reyes & Lanner 2017). The first argument is grounded in the importance of procreation for individuals’ well-being and for their flourishing. The argument of reproductive freedom states that people should be free to decide in matters of procreation and that no third-party should interfere with such freedom (if no harm is foreseen) (Harris 1992; Robertson 1994). Genome editing would enhance prospective parents’ reproductive freedom as it would allow them to pursue their preferred life plan (i.e., having children) in the way that most resonates with their wishes and desires (i.e., having genetically related children who are free from the genetic mutation they themselves carry). Another argument in favour of genome editing focuses on the benefits of using this technology in the context of assisted reproduction for the offspring and for future generations in general. For instance, Harris (2015) argues that:

All of us need gene editing to be pursued, and if possible, made safe enough to use in humans. Not only to pave the way for procedures on adult tissues, but to keep open the possibility of using gene editing to protect embryos from susceptibility to major diseases and prevent other debilitating genetic conditions from being passed on through them to future generations. (Harris 2015)

Genome editing would allow for the editing of the genetic makeup of IVF embryos in vitro, who would consequently develop into mutation-free offspring. Genome editing would prevent the occurrence of genetic diseases both in the first generation offspring as well as in future generations, while PGD can sometimes only prevent

the occurrence of genetic diseases in the child who develops from the implanted embryo (Gyngell et al. 2017).

### 3.5 How Do We Argue About New Technologies?

Let me take stock of what I have said so far. There are certain arguments against the use of genome editing (where germline modification and concerns with the safety of this technique are concerned) as there are arguments in favour of its use (where prospective parents' reproductive freedom and children's welfare are concerned). What then? How are we going to find a path through what Greene (2014) describes as the "morass of competing moral values" (Greene 2014: 185) (henceforth simply 'the morass' or the 'moral morass') and move towards a debate on new technologies that can constructively foster institutional design?

In this section, I focus on what I see as deep disagreement regarding both the moral standing of genome editing and the regulatory approaches that can be put in place. I explore different strategies that could be employed to overcome this deep disagreement, while indicating the foreseeable obstacles to the completion of this task. The first two options (and the related strategies) are what I see as the business of bioethics, or at least the business of many scholars working in bioethics. One option is to focus squarely on the disagreement by politely pointing out to those who hold a different moral view or by leveling the accusation at them that they are committing factual mistakes: they have failed to grasp how science and technology really work. The second option for dealing with existing disagreement is to try to persuade them of, or (at worst) to force onto them certain moral views by using sound philosophical arguments.

In my view, both options and the related strategies to overcome the deep disagreement are theoretically flawed and may result in states of affairs that do not promote our well-being. In the first two sections I explain why I believe these two strategies will not bring us through the morass. Then, in the last section, I provide some insights from moral psychology and argue that that literature can help us going forward to build a debate that can constructively aid the development of policies for the regulation of new technologies.

### 3.5.1 Option 1: It's All a Matter of Facts

One possible interpretation of the disagreement is to think about it in terms of a *misunderstanding of the relevant facts* of genome editing. This is an appealing interpretation as it could offer a potential strategy (the path through the morass that we are seeking) for overcoming the disagreement: getting the facts straight.

This interpretation is implicitly and, in certain instances, explicitly endorsed by those who criticise the arguments of other scholars for holding a different moral view concerning a new technology. Both groups often hint at the incapacity of 'opponents' to understand how policy-making, scientific research, or the respective technology work. Consider the questions of uncertainty and safety. Both sides (those in favour of continuing genome editing research and those who oppose it) agree that, at present, it would be premature to use genome editing in the context of assisted reproduction and that the primary application of genome editing should be research-oriented. The problems (and the disagreements) arise when future applications are speculatively considered, and when the question is posed concerning when, if ever, genome editing applications on human embryos will become more successful (e.g., when they might have fewer off-target effects, or cease to give rise to mosaic embryos). For proponents of human genome editing the questions of uncertainty and safety are seen as contingent, rather than fundamental, impediments. For them, conducting experiments genome editing will lead to overcoming impediments such as mosaicism, to decrease the off-target effects and to increase the reliability of the technology. They focus on *when* (rather than *if ever*) genome editing will be safe enough to proceed. On the contrary, those who are sceptical about the benefits of the technology, or who oppose it in principle, consider questions of safety to be the end of the debate rather than the beginning, a reason not to carry out potentially dangerous research rather than a reason to further pursue technical knowledge. They see the impediments described above as evidence for current (and often future) unsafety of the technology.

So, what are the relevant, the right facts? And, especially, can scientists, policy-makers and ethicists settle once and for all the questions of uncertainty and safety? Spoiler alert: I argue that it is highly unlikely that they are able to do so. Other

debates about whether new assisted reproductive technologies should be allowed can help to illustrate how safety-questions are rarely a matter of factual disagreement alone.

Two techniques for the replacement of maternal mitochondrial DNA in embryos created with IVF, using the genetic material of the prospective parents and the mitochondrial DNA of a donor, have been recently approved (2015) in the United Kingdom. The decision of Parliament to approve these techniques was surrounded by a heated debate both within the United Kingdom and abroad. In a lively exchange between John Harris and Inmaculada de Melo-Martín, two philosophers who work in the field of bioethics, the question of safety was extensively discussed (Harris 2016a; de Melo-Martín 2017b). Harris, a known proponent of MRTs and other assisted reproductive technologies, argued that the right question to ask was not whether MRTs were “safe”, but whether they were “safe enough, given the balance of risks and benefits”, adding that MRT “from a safety perspective was regarded as good to go” (Harris 2016a: 10-11)<sup>89</sup>. On this very same point (uncertainty and safety) de Melo-Martín responded: “[c]ontrary to Harris, I believe that the evidence about the safety of these technologies is at this point completely inadequate” (de Melo-Martín 2017b: 161).

So, are MRTs safe or not? What are the facts of the matter? What does the evidence tell us? One possible answer is that either Harris or de Melo-Martín is simply wrong and has failed to understand correctly the scientific evidence regarding the safety of these techniques. Certainly, Harris thinks so about de Melo-Martín (and possibly vice versa), but this is precisely the point. Either one of them is right and the other is wrong (factually, that is), or there must be an alternative explanation for the disagreement<sup>90</sup>. And the very existence of such disagreements between two

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<sup>89</sup> Harris here refers to the multiple reviews of the ‘scientific methods to avoid mitochondrial diseases’, carried out in the United Kingdom by the Human Fertilisation and the Embryology Authority (HFEA) in 2011, 2013, 2014, and 2016, prior to the approval of MRTs in the U.K.

<sup>90</sup> It is important to note that I believe that Harris is right in considering safety-questions in terms of “safe-enough” questions. When I say that one of them is right and the other is wrong I do not refer to their assessments of what safety means, but rather to questions regarding the benefits of MRTs. These questions, as I explain below, are in my view not entirely matters of fact.

respectable scholars<sup>91</sup>, and especially within scientific, bioethical, and political communities, should set alarm bells ringing.

Safety is largely a contextual matter<sup>92</sup>. As Harris rightly points out, to say that a certain technology is “safe” hinges on how its risks and especially its benefits are evaluated – and how costs and benefits would be distributed. In other words, risks and benefits are contingent on the position of individuals in socio-economic, geopolitical, gender related and other aspects, and are very often unevenly distributed across the population (Prainsack & Buyx 2011)<sup>93</sup>. Whether a technology is considered safe also depends, crucially, on whether approving the technology in question would violate principled positions in favour and against technological developments more generally (or principled positions regarding that specific technology). Principled positions, positions regarding what is morally right and wrong, being derived from higher moral principles<sup>94</sup>, influence our understanding of the science of genome editing and our assessment of the risks that the technology may pose to future generations. This does not mean that it is impossible to assess the safety, the risks or, more generally, the facts of scientific breakthroughs, nor that we should give up trying to do so. It also does not mean that we blindly follow high moral principles to the point of drawing conclusions that are independent of previous reflections, conversations, and our own intellectual work in general. It simply means

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<sup>91</sup> I am not saying that respectable scholars are never factually wrong, but I am favouring an alternative interpretation to explain this specific disagreement.

<sup>92</sup> Importantly, considering safety a contextual matter does not mean either that it is impossible to hold a realist position regarding science and technology, or that we should give up trying to assess the safety of new techniques. For a discussion (and defence) of objectivity and realism in scientific research, see, for instance, Kitcher (2001).

<sup>93</sup> Additionally, as I argue elsewhere, the ethical assessment of new techniques ought not only to rest on a cost/benefit analysis, but also on an evaluation of existing alternatives, including those that do not rely on biomedical means. In other words, whether genome editing really represents a worthy alternative to existing options (such as PGD) depends on the extent to which the welfare of the future child can be put at risk in order to allow couples to have a genetically related child. Regulators and ethicists that argue in favour of eventually replacing PGD with genome editing, and couples for whom PGD does not represent an option, will have to consider whether reproductive autonomy should trump questions about the welfare of the child, in light of uncertainty (Cavaliere 2018a).

<sup>94</sup> When I say that these positions are derived from higher moral principles I do not mean that they are consciously derived from these principles, but that peoples’ moral judgements are informed and derived by more general principles about right and wrong.

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that principled positions play a role in these assessments. While not denying that some empirical questions will be eventually put to rest, it is nevertheless important to note that a consensus on the question of safety will be hard to reach, due to the competing values at stake in stakeholders' assessments. Those who take a precautionary stance concerning technological development will favour existing technologies over newly discovered ones, while those generally in favour of technological development will be ready to accept a higher degree of risk in the name of such development and of the potential benefits it may yield for those in a position to enjoy such benefits (Prainsack & Buyx 2011).

In the past two decades, moral psychologists have shown how moral intuitions (i.e., intuitions regarding the rightness and the wrongness of a certain practice) play a role in the formation of moral judgments, and how the rational argument that follows is a *post hoc* rationalisation of the initial, intuitively formed, judgment (Greene et al. 2001; Haidt 2001, 2012). These principled positions against or in favour of a certain practice (or technology) are not derived after a thorough assessment of the risks, the benefits, the safety etc. of the practice, but intuitively and automatically, prior to the thorough assessment of the available evidence (Haidt 2012; Greene 2014). According Haidt (2001, 2012) and other moral psychologists (Greene et al. 2001), moral judgment is not the end point of a rational process in which, like zealous judges, people collect the available evidence (for example, regarding the safety of genome editing), thoroughly assess it, and only then come to a certain moral conclusion (say, a green or a red light for genome editing in the areas of basic research or assisted reproduction). When we argue about moral questions and moral beliefs people are more akin to lawyers who try to defend their original thesis (i.e. genome editing is safe enough or is not safe enough) by constructing a *post hoc* rational justification for it (Baumster & Newman 1994; Ditto et al. 2009; Haidt 2001, 2012). As Wright puts it:

The brain is like a good lawyer: given any set of interests to defend, it sets about convincing the world of their moral and logical worth, regardless of whether they in fact have any of either. Like a lawyer, the human brain wants victory, not truth. (Wright 1994: 280)



The principled positions that we hold inform our assessment of safety, risks, and benefits. They inform, in other words, the facts of the matter regarding a certain practice. It is not only that evidence in psychology shows that we are all very good at finding evidence that resonates with our principled moral position and with our beliefs in general. Studies focusing on the so-called ‘confirmation bias’ (Shaw 1996), on ‘motivated reasoning’, and especially on ‘motivated moral reasoning’, show that we are much more likely to be sceptical and to question evidence that contradicts our principled position than evidence that supports it (for a review of the relevant social psychology literature, and a discussion of ‘motivated moral reasoning’, see Ditto et al. 2009). Motivated moral reasoning describes situations in which “judgment is motivated by a desire to reach a particular moral conclusion” (Ditto et al. 2009: 312). Thus, these are:

[S]ituations in which an individual has an affective stake in perceiving a given act or person as either moral or immoral, and this preference alters reasoning processes in a way that adjusts moral assessments in line with the desired conclusion. (Ditto et al. 2009: 312)

Even if we have a conscious preference for objectivity in judgment, we often have unconscious directional motivations to reach certain conclusions that are preferred over others. This, again, does not mean that we are unable to reason ourselves away from such conclusions, nor that motivated moral reasoning is a robust and unmodifiable characteristic of the moral mind. It just means that we need to be aware of our own biases, preferences and moral views when we assess the evidence regarding, for instance, the safety of a new technology.

Harris, Savulescu, and others are known proponents of new technologies. De Melo-Martín, Baylis, and others who have argued against genome editing and MRTs, have held similar position with respect to other new technologies. Moreover, all of them are seasoned bioethicists capable of reading scientific papers correctly. Yet, for all of them, safety questions are either insurmountable or merely a contingent matter. So, who holds the truth of the matter concerning the safety of genome editing? The psychological literature on the role of moral intuitions in assessing the evidence, as well as the deep disagreement among bioethicists, scientists and policy-

makers concerning safety questions, seem to provide at least a *prima facie* reason to be sceptical that to overcome the disagreement it would be sufficient to merely getting the facts straight. This makes the idea of grounding a broad consensus on facts alone a very risky project.

### 3.5.2 Option 2: May the Best (Argument) Win

Another strategy for overcoming the disagreement (which, I hope we have established, is at least also a moral disagreement) is to play the philosophers' beloved game and stage a good old rhetorical battle in which the best argument wins. Applied to the context of genome editing and assisted reproduction, with the (regrettable) impossibility of organising a global debate competition, the strategy would be to assess the arguments in favour of and against genome editing. This appears to be a good idea, and indeed almost the entire business of certain philosophical and bioethical traditions has been about doing exactly this. To assess the arguments in favour of and against the use of genome editing in assisted reproduction we could check for logical mistakes, for inconsistencies, for the correctness of the premises, and for the soundness of the conclusions. Yet, should we then also attempt to evaluate moral arguments on the basis of the state of affairs that the normative positions will bring about? Or should we focus on the arguments' resonance with a universal moral law? Or on what the arguments say about the moral character of the speaker? The appraisal of philosophical arguments, the different methods for conducting such an appraisal, and the conditions for an argument to be valid are disputed. What matters for the present discussion is that we be able to agree on certain minimal standards an argument should meet in order to be considered in the debate on genome editing. Nevertheless, I fear we would be left again with sound, logically valid, but still contradictory arguments.

Häyry (2010), for instance, talks about the different moral arguments, in favour of and against new genetic technologies, in terms of competing rationalities'<sup>95</sup>. These

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<sup>95</sup> Häyry (2011), defines rationality in "nonconfrontational" terms: "A decision is rational insofar as it is based on beliefs that form a coherent whole and are consistent with how things are in the world;

are divergent rational moralities that can be simultaneously held. According to Häyry, then, we should resist the temptation to compare such rationalities and elevate one of them above the others. Instead we should limit ourselves to checking for internal the consistency of the argument and their external consistency with how things are in the world (Häyry 2011). So, for instance, it is uncontroversial to reject as a fallacy the argument ‘germline modifications are morally wrong because yesterday my grandma told me so’ (arguments from authority should set off the alarm bells), or equally, arguments that are incoherent and inconsistent. However, it may be much harder to likewise reject arguments that defend positions like the following ones: ‘germline modifications are morally wrong because they could be harmful to the children born as a result of the application of CRISPR’; or ‘germline modifications are morally obligatory because they enhance parents’ reproductive freedom, which is a fundamental moral right’<sup>96</sup>.

Fallacious, illogical arguments can and should be criticised, especially in matters of science and ethics (Harris 2011). This is what participants in the debate on the ethics of genome editing (and other assisted reproductive technologies) do on an almost daily basis. There are two problems with this strategy, if our goal is not to find the best philosophical argument (i.e., ‘do moral philosophy’), but to build a space where coexisting moral positions are discussed and some degree of common ground is found (i.e., to ‘do public policies with insights from moral philosophy’, and, I contend, moral psychology)<sup>97</sup>. In these debates, the best argument – one that shows

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and it is aimed at optimising the immediate or long-term impacts on entities that matter” (Häyry 2011: 43)

<sup>96</sup> Personally, I am very sceptical of deontological arguments appealing to nature, sanctity, or rights. What I want to highlight here is that it is a very complex and perhaps unfeasible task to a) find an independent way to evaluate these arguments (i.e., an evaluative strategy that is not dependent on one’s own moral and meta-ethical convictions), and b) to agree on who should decide which strategy is the most appropriate. For a thorough case against appealing to rights, see Greene (2014, Chapter 11, Part V).

<sup>97</sup> One might say that the business of bioethics is not to build a space for a mutual exchange regarding differing moral positions, but to let the “best” moral argument win. Besides the procedural problems briefly described above, what we are trying to achieve here (i.e., what I am discussing in this chapter) is broad societal consensus as well as finding at least some common ground to move forward in the debate on genome editing, and building a regulatory framework that helps to alleviate “the burden of human existence” (Harris 2016a), whilst still accommodating opposing views as much as possible.

no logical mistakes, while exhibiting internal consistency, relying on valid premises and inferring valid conclusions – rarely *wins*. In other words, even if we agree on an independent strategy to establish who should win the prize<sup>98</sup>, and even if we pursue this strategy, we are left with a very good argument that may still fail to convince people who hold a different moral view (Camporesi & Maugeri 2011). We are left with, as Camporesi and Maugeri (2011) put it: “a cornucopia of ethical perspectives, each internally consistent but providing mere philosophical amusement.” (Camporesi & Maugeri 2011: 255) This is a common problem in bioethics and in moral philosophy in general. An example: the argument that genome editing should be allowed, since it is in the interests of prospective parents to choose their preferred reproductive method, and to have their freedom in matters of procreation respected, is an argument that may be more intuitively appealing for someone who a) holds dear reproductive autonomy and freedom in general, and b) is sympathetic to the idea that reproductive freedom promotes well-being is an important value that should be respected. What I mean is that the pull of this argument may work on people who believe that freedom in matters of reproduction should trump other considerations, but not on those who, for instance, hold that assisted reproductive technologies are a mere commodity, and that research agendas should prioritise other, more pressing issues.

Besides these problems (of persisting moral disagreements and competing values), the problem with the “best argument” approach to the ethics of genome editing is that, even if it was possible to overcome the procedural challenges in selecting it, we may still not win as a community and as individuals. In other words, what we are faced with is not a philosophical problem, but a political problem. We may have very good arguments, sound and valid philosophical arguments, which still fail to promote our well-being and our happiness (broadly conceived, that is: independently from one’s own conception of well-being), which is arguably what these technologies, and perhaps medicine in general, should promote.

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<sup>98</sup> See note 16 above for an explanation of ‘independent strategy’ and of the procedural problems that we may encounter.

### 3.6 Perhaps not Everything is Lost. The ‘Listening Mode’ and the ‘Meta-Morality’

If my arguments (and some of the evidence from moral psychology) have managed to convince you, then at this point you should be at least a little sceptical of two options for overcoming the disagreement concerning the use of genome editing in assisted reproduction: explaining the facts of the matter to those who still fail to understand them, and letting the best argument win. Both strategies are, in my view, theoretically flawed and may end up bringing about state of affairs that do not promote our well-being. The deep moral disagreement surrounding genome editing technologies and their applications seems to be an obstacle we cannot ignore, if we want to move forward (by either banning or regulating applications of these technologies). What then should we do?

A possible diagnosis of the deep moral disagreement we experience in our everyday lives is that we have different moral intuitions and we hold different moral beliefs (Greene 2014; Haidt 2012). Religious scholars, feminist scholars, liberal philosophers, critical theorists, and lay people who find themselves embedded in differing political, socio-economic and cultural context, react in differing ways to contemporary (moral) controversies. Gay marriage, redistribution of income and wealth, but also debates about abortion and genome editing, stir controversy because we hold different moral views, some of which are *post hoc* rationalisation of differing moral intuitions. Moral psychologists Jonathan Haidt and Joshua Greene offer different normative prescriptions for overcoming the disagreements and learning to cooperate between different moral tribes. In this final section of my chapter I briefly outline their normative prescriptions. My conclusion is that they are both illuminating for the way we reflect on genome editing and the way we develop strategies to regulate new technologies beyond national borders.

Haidt’s social intuitionist model (Haidt 2001, 2012) shows that people are good at finding evidence that confirms their initial moral judgment (remember the lawyer analogy!). What can make us change our minds about our moral beliefs is the multiplicity of occasions where we find ourselves challenged by others (what Haidt calls “reasoned persuasion”, Haidt & Björklund 2007), and by the social

environment in which we are embedded (what Haidt refers to as ‘social persuasion’<sup>99</sup>, Haidt & Björklund 2007). Moral reasoning needs to be understood in terms of a social process, in which people embark alone on the search for evidence and come together for the appraisal of such evidence. We need to be aware that we are self-righteous creatures, with a tendency to form moral beliefs from our intuitions and to rationalise them afterwards in our exchanges with others. To better get along with each other, and to find a path through the moral morass of genome editing, we need to acknowledge that our disagreements do not necessarily and solely stem from factual mistakes, wrong arguments, and wrong moral beliefs<sup>100</sup>, but from our competing rationalities and differing intuitions. Haidt’s central normative prescription is to be more open towards those who hold views different from ours, to be aware that we are all biased by our moral intuitions (all of us, not only those who disagree with us), and to be aware that some of our grand arguments may simply be *post hoc* rationalisations of gut feelings. Thus, the Haidtian path through the moral morass of genome editing encourages us to abandon the mode of combat, and put ourselves in the listening mode, when we discuss the ethics of genome editing, its applications, and the regulatory frameworks which should be adopted.

Greene (2014) accepts Haidt’s premises, shares his evolutionary understanding of morality, his view on the role of intuitions in the formation of (only some types of) moral judgments, and importantly, his (above outlined) normative prescription. However, despite this broad agreement, he argues that Haidt’s normative prescription alone will not bring us much further in our moral disagreements. In other words, listening and being open to opposing views are all good strategies as far as

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<sup>99</sup> Social persuasion refers to the fact that persuasion does not only happen when others give us reasons, arguments or new evidence, but also simply by virtue of our being “sensitive to and influenced by what other people think and feel” (Haidt & Björklund 2007: 192).

<sup>100</sup> By wrong moral beliefs, I mean the moral beliefs that we do not share and that we may have failed to understand.

they go, but they are unlikely to bring us forward, if broad societal consensus<sup>101</sup> is what we aim for.

Over the last 20 years, Greene has examined the brain scans of people while they were reflecting on moral dilemmas such as the trolley problem<sup>102</sup>. Greene observed that different areas of the brain (the ventromedial prefrontal cortex, VMPFC, and the dorsolateral prefrontal cortex, DLPFC) showed more activity depending on which variation of the trolley problem was proposed. The footbridge case elicited more brain activity in people's DLPFC, the brain area associated with more logical, calculating cognitive capacities. On the contrary, more impersonal dilemmas such as the switch case elicited more brain activity in the VMPFC and in the amygdala, the brain regions associated with emotions. The only difference between the footbridge case and the switch case is whether the man scarified to save five is directly pushed down from the bridge to the track (and hence killed to prevent the trolley to kill the other five people) or he is killed by hitting a switch that diverts the trolley from a track where five people are standing to the track where he is standing. In a series of experiments conducted by Greene and others they verified over and over how brain activity in the DLPFC was linked to choosing utilitarian solutions (i.e. killing one to save five), whilst activity in the VMPFC was linked to dilemmas that involved directly pushing and hence killing a person to save the other five. This led Greene to formulate the theory of the dual-process brain (or of the two moral minds), delineating the process that works in automatic-mode and it is guided by our

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<sup>101</sup> Greene does not aim at broad societal consensus alone. He has a normative theory in mind for how that broad consensus ought to look. However, a discussion of his proposal is beyond the scope of this chapter.

<sup>102</sup> The trolley problem describes a cluster of moral dilemmas that are all characterised by the choice of sacrificing one person in order to save five. The trolley problem was first discussed by Philippa Foot (1967) in an article discussing abortion and the doctrine of double effect. Different version of the problem and an analysis of the moral views that underpin them were later discussed by Judith Jarvis Thompson (1976). The two variations I am referring to here are the 'switch case' and the 'footbridge case'. The trolley problem describes a situation in which a runaway trolley is barrelling down one track where there are five people tied up and unable to move. On another track there is one person, also tied up to the track and unable to move. In the switch case, a bystander could pull a lever and divert the trolley onto the track where only one person is tied up. In the footbridge case, the trolley is still barrelling down a track where five people are tied up and unable to move, but the only way the bystander can stop the trolley and prevent their death is by pushing a fat man (or a man with a large backpack) off a bridge. In both cases, the choice is between killing one person to save five or do nothing and let these five people die.

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unconscious, automatic, emotional responses, and the process that works in manual-mode and has “conscious access to the operative decision rule. The rule that maps the relevant features of the situations onto a suitable behaviour” (Greene 2014: 136). According to Greene’s dual-process theory:

Reasoning frees us from the tyranny of our immediate impulses by allowing us to serve values that are not automatically activated by what’s in front of us. (Greene 2014: 137)

We still need the input of emotions for decision-making, for evaluating risk (Damasio 1994), and for avoiding the conflicts that hinder cooperation among members of the same moral tribe, but we also need more than this (Greene 2014).

Greene’s normative prescription is that we need something more than emotions, than the automatic mode, to avoid conflicts between tribes that are moral in differing ways. Listening, avoiding self-righteousness and being more open for compromise are good steps. However, they are only first steps. We need all this and more to find a path through the moral morass. We need to work in manual mode to develop what Greene calls a ‘meta-morality’:

A global moral philosophy that can adjudicate among competing interests of its members. A meta-morality job is to make trade-offs among competing tribal values, and making trade-offs requires a common currency, a unified system for weighing values. (Greene 2014: 15)

The manual mode, the one that makes us choose to kill one person to save five in both the variations of the trolley problem, is the mode that causes us to reflectively endorse the greater good. The mode that overrides the emotional rejection of killing an innocent person in the name of the greater good (saving five people) is utilitarian morality (which Greene calls ‘deep-pragmatism’). Greene’s view that utilitarianism is a ‘splendid idea’, one we should all endorse, or at least strive to endorse in order to overcome our tribal conflicts, is an interesting view. It is also very controversial and has been criticised for a number of reasons, including the fallacy of deriving normative conclusions from factual claims (from the brain scans to deep-pragmatism as the morality that we ought to embrace), and critiques that are normally put forward against utilitarianism in general.



Despite the criticisms and despite detractors of utilitarianism, I think there is a lesson to be learned from Greene's proposal. What we need is to develop a meta-morality that causes us to transcend our tribal disagreements and that allows us to discuss together 'what matters' (Parfit 2011). The Greenian path through the moral morass of genome editing encourages us to find a common moral language, shared values, and shared moral beliefs as a starting point for discussing the ethics and policy questions of genome editing.

### 3.7 Conclusion

A decision about allowing genome editing in the context of assisted reproduction has to rest not only on a thorough assessment of the safety of the techniques, and their possible or likely benefits, but also on a democratic process that takes into account differing views and values (Cavaliere 2017; Jasanoff et al. 2015; Kitcher 2001). In this chapter, I have focused on genome editing in the context of assisted reproduction, and on the calls for broad societal consensus in tackling this question. I presented two main arguments against this possibility: namely, safety and that these applications would lead to germline modifications. I then turned to arguments in favour of genome editing, such as the welfare of future children and peoples' reproductive autonomy. As many have argued, it may be too soon for a conclusive assessment of this possibility, if only for the dearth of empirical data regarding its safety and feasibility. Thus, what this chapter offers a basis to begin a discussion on the ethics of genome editing that is informed by the literature in moral psychology. I argued that we should focus on finding a common currency and shared moral values, a meta-morality that goes beyond the deep moral disagreements among us, and that allows us to speak a common language that enables a minimum of agreement among us.

### 3.8 Declaration

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#### 4 Conclusions to Part I

In this final section of Part I, I present some of the implications of the arguments advanced in Paper 1 (Cavaliere 2018d) and Paper 2 (Cavaliere 2018c) and recommendations for debates on the ethics of new reproductive technologies. These papers include sources that go beyond the application of theories in moral philosophy to debates on new reproductive technologies, and beyond well-established dichotomies such as those discussed with respect to eugenics (e.g. coercion/freedom, and individual/population; see also Bashford 2010). In these papers, I also adopt a reflective and critical attitude to the claims and arguments advanced within these debates.

As many authors have argued, eugenics is a word with manifold negative connotations and with the potential to trigger resistance towards new reproductive technologies. This happens largely due to the tainted history of policies enacted in its name and of condemned practices inspired by eugenic thinking. Referring to eugenics within debates on the ethics of new reproductive technologies and employing other loaded words, metaphors, and expressions can have the effect of leading the moral judgements of those who participate in debates on these technologies in an author's preferred normative direction.

In the introduction to this part of the thesis and in Paper 1, I argued that reference to eugenics should be treated as a handle-with-care tool within debates on the ethics of new reproductive technologies. While care should be observed, looking into the shadow of eugenics and learning about its historical unfoldings continues to be an endeavour that in my view needs to be pursued. As Lombardo (2018) argues:

Although I do not favor the ever-present commercial genetic exuberance, it does not help routinely to call that trend eugenics either. We should debate the ethical issues that arise in reference to all those new technologies, but we have plenty to be concerned about that fits more directly into patterns that mimic our troubled history of eugenics, without using that term indiscriminately to describe every new phase of genetic research. (Lombardo 2018: 5)

Following Lombardo (2018), authors discussing the ethics of new reproductive technologies should be especially concerned with ideas and practices that resemble problematic features of the history of eugenics. This should not translate into employing eugenics as a 'cautionary tale' (Paul 1992), but rather as a heuristic to aid analytical understandings and normative assessments of the present.

I have also argued that authors who choose to refer to eugenics should strive for conceptual clarity and descriptive accuracy. They should strive to adopt a self-reflective attitude and to pursue other strategies to persuade others, which would involve employing reasonable and philosophically sound arguments in addition to emotive language. Descriptive accuracy can be instrumental to the adoption of a self-reflective attitude towards one's own claims. At the same time, it can also empower (other) participants to clarify, refine, and question their ethical views, and to produce ethical assessments of these technologies. With respect to the reference to eugenics in debates on new reproductive technologies, descriptive accuracy entails that the historical unfolding, and the different practices, policies, ideologies, and beliefs about heredity that characterised 20<sup>th</sup> century eugenics must be known and acknowledged in authors' depictions of eugenics. Saying that a certain reproductive technology is eugenic without having a good understanding of the history of eugenics is not only an instance of poor academic practice, but can also be misleading in that other participants in these debates could get 'a wrong idea or impression' (cf. the *Oxford Dictionary* definition reported above) of the ethical challenges raised by new reproductive technologies. In addition, if this history is known and, despite this, the word 'eugenics' and the definition of it that is employed in debates on the ethics of these technologies does not accurately depict 20<sup>th</sup> century eugenics, then the word is used deceptively, namely to 'deliberatively cause someone to believe something that is not true' (cf. the *Oxford Dictionary* definition reported above). This would amount to another instance of methodologically and normatively troubling practice within these debates. Lastly, this lack of explicit engagement with the history of eugenics is problematic as it prevents the creation of a common ground to discuss ethical questions raised by the technologies being compared with this history.

It can also be the case, however, that the differences in terms of ethical assessments of the history do not necessarily mean that one side is (factually) wrong: there can be competing assessments of the 'same' history. These competing assessments, as I argued above, result from diverging values and world-views on the ethical standing of decisions at the core of eugenics: namely of who should come into existence, and of how to balance the burdens and benefits of these decisions. The second endeavour that should be promoted and pursued within debates on the ethics of new reproductive technologies, and that, when lacking, may render problematic references to eugenics, is self-reflection. If in the eyes of some authors, MRTs, genome editing, PGD, and other new reproductive technologies embody wrongful and despicable practices such as those carried out in the name of eugenics, then these practices and the reasons why they are despicable should still be part of debates on new reproductive technologies. Learning from history (even considering the different ethical assessments of this history) entails both knowing what happened and striving to avoid repeating mistakes. However, as I argued earlier, referring to eugenics should be done carefully. Thus, for instance, reflecting on why one believes certain new reproductive technologies are eugenic then asking oneself which features of these technologies or of their uses engenders the thought of eugenics; which features of the past can be seen in the present; what are the emotive and intuitive reactions to these technologies, etc. This allows a self-reflective attitude to emerge. Being self-reflective entails an awareness of one's biases, intuitions, and emotions, as well as underlying values and beliefs, which could foster attitudes seeking to avoid misleading others.

Lastly, how should one deal with moral disagreement on new reproductive technologies? The answer is: it depends. It depends on what bioethics and debates on the ethics of new reproductive technologies aim to offer. If the only goal of debates on the ethics of new reproductive technologies is a quest for truth and to present knockdown arguments<sup>103</sup>, then moral disagreement may not need to be dealt with. After all, as Wolff (2011) puts it:

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<sup>103</sup> For a discussion of knockdown arguments see, for instance, Nathan Ballantyne (2014).

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[P]hilosophy thrives on disagreement, and there is no pressure to come to an agreement. Indeed agreement is unhelpful as it cuts discussion short. (Wolff 2011: 3)

Despite this, if debates on the ethics of new reproductive technologies are to contribute in meaningful ways to policy-making, deep moral disagreement may be an obstacle. Focusing on listening to others, abandoning a combative mode, and finding a common moral language of shared values may be strategies worth trying.

# PART II

## The Ethics of New Reproductive Technologies

### 1 Introduction to Part II

The second part of this thesis involves a shift of focus. Part I was largely concerned with a reflection on, and an analysis of debates on the ethics of new reproductive technologies. In the two papers incorporated into Part I, I described and discussed the reference to eugenics within these debates, the moral disagreement that surrounds new reproductive technologies (using genome editing as a case study), and the argumentative strategies pursued within these debates. In Part II, I address ethical and social questions raised by new reproductive technologies and their clinical applications. In particular, I discuss ethical and social questions raised by the clinical application of genome editing technologies to early human embryos and by MRTs. Besides a change of focus, Part II also entails a shift in terms of aims. In Part I, my aim was mainly methodologically oriented and concerned with offering examples of how debates on the ethics of new reproductive technologies can be enriched by including different disciplinary sources. Here, my aim pertains more specifically to the question of who should come into existence, and of how to balance the burdens and benefits of these decisions.

In the two papers incorporated into this part of the thesis (Paper 3, Cavaliere 2018a, and Paper 4, Cavaliere & Palacios-González 2018), I present some of the main arguments in favour of and against MRTs and genome editing and give an overview of the ethical debates surrounding these technologies<sup>104</sup>. In Part I, I laid the foundations for assessing the ethical challenges raised by new reproductive technologies by analysing normative debates surrounding them. Part II represents a step forward to achieve this aim. Here, I specifically discuss the ethical challenges

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<sup>104</sup> In this part of the thesis, I do not provide an extensive review of debates on the ethics of CRISPR (the genome editing technology that I discuss here) and MRTs. Several of the papers incorporated into the thesis contain elements of such a review, as it provided a starting point to develop the ideas that I present and discuss in this part of the thesis and elsewhere.

raised by these technologies and advance my proposal of how they should be ethically assessed. My analysis focuses on two ethical questions and corresponding challenges, namely:

- a) Do these technologies affect the numerical identity of the embryos to which they are applied? What are the implications of considering them identity-affecting technologies?
- b) How should a person's preference for genetically related children be weighed against other considerations (such as those pertaining to resource allocation and negative externalities of new reproductive technologies)? Should new reproductive technologies be developed in order to satisfy people's preference for genetically related children?

As the papers incorporated into this part of the thesis (and the reflections outlined in the conclusion to it) show, these questions and their ethical implications are tightly interlinked.

Paper 3, the first paper incorporated into this part of the thesis, is a single-author paper published in *Medicine, Health Care and Philosophy* titled 'Genome Editing and Assisted Reproduction: Curing Embryos, Society or Prospective Parents?' This paper provides an ethical assessment of the application of genome editing technologies to human embryos to edit potentially harmful genetic mutations<sup>105</sup>. It juxtaposes genome editing with existing technologies such as PGD, which are employed to achieve similar aims (i.e. establishing pregnancies with embryos that are genetically related to their prospective parents and free from harmful genetic mutations) albeit with different means. I consider both genome editing and PGD to be reproductive technologies due to their instrumental roles in allowing people to pursue their (genetic) parenthood projects. These technologies (and MRTs, which are discussed in Paper 4, Cavaliere & Palacios-González 2018) raise the question of

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<sup>105</sup> Some authors have focused on this question and provided arguments for and against this application of genome editing within the broader ethical debate on the ethics of genome editing (see, for instance, Bauman 2016; de Wert et al. 2017; Gyngell et al. 2017; Savulescu et al. 2015). In addition, several reports on genome editing discuss this question, including the National Academies of Science, Engineering and Medicine report (National Academies of Science, Engineering and Medicine 2017) and two reports by the Nuffield Council on Bioethics (2016, 2018).



who should come into existence, as their applications influence the genetic endowment of future generations. This latter feature, with some caveats that I discuss in the next section, fits my proposed definition of ‘eugenics’. Paper 3 directly addresses the central ethical question of this thesis, who should come into existence, and the implications of this decision. It does so by evaluating whether new technologies should be developed and implemented considering existing alternatives, and whether respecting prospective parents’ reproductive freedom justifies their introduction.

Paper 4, the second paper incorporated into this part of the thesis, is an article co-authored with Dr César Palacios-González (CPG) and published in the *Journal of Medical Ethics*. It is titled ‘Lesbian Motherhood and Mitochondrial Replacement Techniques: Reproductive Freedom and Genetic Kinship’. In this paper, my co-author and I discuss the ethical question of extending the criteria of access to MRTs to include lesbian couples wishing to have children who are genetically related<sup>106</sup> to both parties of the couple. MRTs both fit my definition of ‘eugenic’ technologies and have been depicted in the literature as such (see, for instance, Wrigley et al. 2015 for a critical discussion of this claim). This paper returns to the question of the reach of prospective parents’ reproductive freedom, and whether just limits can be imposed on this freedom. I discuss these aspects in Paper 3 (Cavaliere 2018a) and in Part IV of this thesis.

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Despite the public and academic attention it has received, the clinical application of genome editing on human embryos and their subsequent implantation to start a pregnancy is not legally permitted in any jurisdiction (for a discussion, see for instance Araki & Ishii 2014; Braun & Dabrock 2017; de Miguel Beriain 2017; Scott & Wilkinson 2017). At present, the technical challenges of reducing off-target mutations and mosaicism make this application of genome editing not clinically safe

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<sup>106</sup> If MRTs were employed by lesbian couples to this end, the children born as a result of their use would inherit the mitochondrial DNA (mtDNA) of one of the two prospective mothers and the nuclear DNA (nDNA) of the other.

or effective (Vassena et al. 2016). In addition, as some authors have argued, this application may not be necessarily the most pressing from an ethical point of view (see, for instance, Caplan et al. 2015; Charo & Greely 2015; Greely 2015). It may also not be the most pressing in terms of research agendas (other applications of genome editing are already underway) or efficacy and economy of means (other applications may produce more reliable outcomes)<sup>107</sup>. The reasons why I am concerned with this application are on the one hand that it generates controversy and moral disagreement among scientists, ethicists, authors from other backgrounds (such as STS and legal scholars), and members of the public; on the other, that this application of genome editing raises once again the question of who should come into existence<sup>108</sup>.

Moving to MRTs, the technologies discussed in Paper 4, the first country that explicitly allowed MRTs was the U.K., which approved two techniques for the transfer of mtDNA under a licensed scheme after a parliamentary vote in February 2015 (Callaway 2015): mitochondrial spindle transfer (MST) and pronuclear DNA transfer (PNT). In the U.K., ‘The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015’ of the HFEA rule out, albeit not explicitly, other applications of MRTs – such as their use by infertile couples to avoid embryonic arrest and by lesbian couples to have a child who is genetically related to both parties of the couple. Specifically, the HFEA regulations allow the use of MRTs when:

- i) There is a particular risk that any egg extracted from the ovaries of a woman named in the determination [or embryo which is created by the fertilisation of an egg extracted from the ovaries of a woman named in the determination] may have mitochondrial abnormalities caused by mtDNA; and

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<sup>107</sup> For an overview and discussion of alternative applications, see a paper not incorporated into this thesis that I co-authored with Silvia Camporesi: Camporesi and Cavaliere (2016).

<sup>108</sup> I return in the following section to whether genome editing and MRTs can be classified as ‘eugenic technologies’ and whether they are identity-affecting.

- ii) There is a significant risk that a person with those abnormalities will have or develop serious mitochondrial disease. (Human Fertilisation and Embryology 2015)

In Paper 4, I focus on these two conditions and the ethical implications of excluding lesbian couples (and other couples where both parties have functioning ovaries) from accessing these technologies.

I now turn to a discussion of the two questions outlined above, which concern both genome editing and MRTs: namely whether they are identity-affecting technologies and whether a preference to have genetically related children is an ethically acceptable reason to ground a positive case for them.

### 1.1 Eugenic Technologies: Question Mark

In the introduction to this thesis, I argued that the reproductive technologies discussed throughout are eugenic as they play a role in decisions concerning who should come into existence and how to balance the burdens and benefits of these decisions. While for technologies like PGD it is clear that this label applies<sup>109</sup>, within debates on the ethics of technologies such as genome editing and MRTs there is no consensus as to whether they are therapeutic as opposed to eugenic. The debate hinges on a discussion of numerical identity: these technologies would be considered unequivocally therapeutic if their applications to early human embryos (or to oocytes, in the case of MST) did not change their numerical identity<sup>110</sup>. This means that applying, for instance, genome editing technologies to an early human embryo would not give rise to another (numerically different) embryo but to the same

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<sup>109</sup> What is clear is not whether technologies that play a role in decisions concerning who should be allowed to come into existence can be rightfully labelled eugenic. As I showed in the first part of the thesis, this is a contested and controversial label. What seems obvious is that technologies such as PGD do play a role in such decisions. The same cannot uncontroversially be said about genome editing and MRTs, as whether these technologies are eugenic in the sense outlined in the introduction to this thesis is part of the debate on their ethical standing.

<sup>110</sup> I discuss what numerical identity is and what it means to change the numerical identity of early embryos due to the application of genome editing technologies in the first of the two articles that follow this introduction.

(numerically identical) embryo, minus the harmful genetic mutation intended to be corrected. If this was the case, these technologies would not be very different from, for instance, gene-therapy technologies aimed at editing genes responsible for conditions such as beta thalassemia or sickle-cell disease<sup>111</sup>. The only relevant difference would be that the latter technologies are applied postnatally while the former are employed prior to implantation<sup>112</sup>. Similarly, MRTs would be considered eugenic if their applications to early embryos were going to change their numerical identity. If this was the case, these technologies would help to create children free from undesired conditions, rather than treating or, following Anthony Wrigley et al. (2015), ‘pre-emptively’ treating such children<sup>113</sup>.

Whether genome editing and MRTs are eugenic or therapeutic technologies and, especially, the implications of this distinction, are questions discussed in Papers 3 and 4. With respect to genome editing, the ethical implications of this distinction are that, were genome editing technologies therapeutic as opposed to eugenic<sup>114</sup>, they would not be subjected to some of the critiques directed against PGD such as the expressivist argument (Buchanan 1996; Wilkinson 2010, Ch 6). From an ethical

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<sup>111</sup> See Emily Mullin (2017) concerning this application of genome editing technologies.

<sup>112</sup> While I do not think that this is an ethically relevant difference per se, one may argue that applying a genetic technology to early embryos as opposed to grown-up adults or children matters from an ethical point of view. This would be true for those who are opposed to altering the genome of early embryos, as this could be considered an instance of germline modification and as it would require previous studies on embryos (and potentially also discarding embryos involved in this research). Both practices are contested on ethical grounds – I discuss the former in Paper 3 (Cavaliere 2018a) and the latter in Paper 5 (Cavaliere 2017).

<sup>113</sup> For a discussion of claims on genetic identity within the U.K. and U.S. policy frameworks, see Scott and Wilkinson (2017).

<sup>114</sup> The Nuffield Council on Bioethics report (2018), published after the publication of Paper 3, discusses the question of numerical identity and genome editing. It states: “In the case of a serious inherited metabolic disorder, as discussed above, the prospective parents might decide to use a preimplantation intervention to secure that an embryo to be transferred is not affected by that disorder. In this case, if the transferred embryo results in the birth of a child, that child will not have the disorder. The prospective parents might, on the other hand, decide to conceive without assistance. In this case, there is a chance that their child will be affected by the disorder. These two possible children would probably have very different lives. We can also imagine a variation of the first of these two cases (preimplantation intervention) in which the child was not affected by the condition, but their developmental potential was somehow restricted as a consequence of the procedure itself, in a way that did not come to light until after the birth” (Nuffield Council on Bioethics 2018: 64).

point of view, this would provide a *prima facie* reason to defend them, to invest resources to improve their efficacy, and to legalise them. With respect to MRTs, the ethical implications of this distinction are, in my view, broader. As I argue in Paper 4, if MRTs are eugenic as opposed to therapeutic, then their therapeutic potential could not be invoked to ground a positive case for them and to restrict access to them to women at risk of transmitting mtDNA abnormalities to their offspring. Other reasons that can be rightfully said to ground a positive case for MRTs call for expanding criteria to access them beyond the two stated within the HFEA regulations mentioned above. They would call to expand these criteria to include lesbian couples who wish to have children who are genetically related to both parties of the couple.

Despite these clarifications (and further clarifications on this issue offered in Papers 3 and 4), I would still argue that these technologies are, following a broad understanding of the term, as the understanding I am proposing, *eugenic*. An idea that underlies the entirety of this thesis is that eugenics is a widely encompassing phenomenon that concerns decisions on, following Jonathan Glover (1984), ‘what sort of people should there be’ and the implications of these decisions. Notwithstanding the conclusions reached on whether genome editing and MRTs are therapeutic or eugenic in the sense explained above, I contend that at least *the decisions to employ them* to satisfy one’s own procreative and parental preferences as opposed to pursuing alternative routes to parenthood are indeed eugenic in that they cause certain types of people to be brought into existence and not others. What matters for my analysis, then, is not the label itself, but the ethical standing of such decisions and of the technologies which make these decisions possible.

### 1.2 Genome Editing, MRTs, and Genetic Relatedness

Within the debate on the ethics of genome editing, part of the attention has been devoted to ethical questions raised by applying this technology to early human embryos as an alternative to PGD for prospective parents at risk of transmitting genetic conditions to their offspring (see for instance: Bauman 2017; de Wert et al.

2017; Gyngell et al. 2017; Mertes & Pennings 2015)<sup>115</sup>. Some of the authors discussing this issue (de Wert et al. 2017; Gyngell et al. 2017) have argued that, once safety questions have been addressed and sufficient basic and pre-clinical research have been conducted, genome editing could have two comparative advantages over PGD. The first is that it could be used in cases where PGD is not effective (de Wert et al. 2017; Vassena et al. 2016) and the second is that, unlike PGD, genome editing has trans-generational effects in that the changes inserted in the embryos are heritable (Gyngell et al. 2017; de Wert et al. 2017). As stated above, genome editing does not currently represent a viable alternative to PGD due to laws and regulations prohibiting germline modifications and to technical limitations. This means that, at present, the question is not whether genome editing should be used in the context of assisted reproduction as an alternative to PGD, but rather whether public and private resources should be deployed to conduct basic, pre-clinical, and clinical research with genome editing. Contrary to other concerns that have been raised (see, for instance, Baltimore 2015; Baylis & Ikemoto 2017; Collins 2015; Lanphier et al. 2015), regarding human dignity, obtaining informed consent and other deontological objections, I am not convinced that these are compelling reasons against conducting research with genome editing<sup>116</sup>. What I contend instead is that the question of the opportunity costs of allocating resources to basic, pre-clinical, and clinical research with genome editing deserves ethical attention<sup>117</sup>. While this question does not amount to a conclusive reason against conducting research with genome editing, it ought to be considered in assessments of the ethical challenges of the introduction of genome editing as an alternative to PGD (or within discussions of ‘cases for’ and ‘objections to’ this possibility, as in Gyngell et al. 2017).

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<sup>115</sup> For an overview of the arguments for and against, see Guido de Wert et al. (2017).

<sup>116</sup> For a critical discussion and rebuttal of these concerns, see John Harris (2016a); Guido M. W. R. de Wert et al. (2017); Christopher Gyngell et al. (2017).

<sup>117</sup> A similar view is expressed by Heidi Mertes and Guido Pennings (2015) in a brief commentary: “Thus, the only plausible way in which germline editing therapies would provide a substantial benefit as compared to the current standard of care would be when they turn out to be superior to PGD in terms of clinical outcomes, in terms of cost-effectiveness, and/or in terms of ethical concerns” (Mertes & Pennings 2015: 53).

The other few commentators who have compared PGD and genome editing, such as Christopher Gyngell et al. (2017), consider (and reject) objections to genome editing concerning safety, enhancement, and deontological objections against inserting heritable changes in early embryos mentioned above. But these questions, and especially safety questions, do not exhaust the debate on the ethical standing of a new reproductive technology. Safety is of paramount (ethical) importance, and no technology should be approved without a thorough assessment of its risks and potentially harmful consequences. At the same time, focusing only on safety (and on defeatable deontological objections) can engender undesirable outcomes. A first undesirable outcome is that this narrow focus systematically excludes other potentially relevant ethical concerns<sup>118</sup>; another is that it points towards only ‘technical’ solutions to what are perceived as ‘technical’ problems. This means on the one hand that other potential non-technical solutions, such as changing laws regulating adoption and gamete donations, may not be considered worth pursuing; on the other hand, scientists can retain their authority in ethical debates as they are the best placed in assessing safety and efficacy, while other ethically relevant concerns may end up being systematically excluded (Hurlbut 2017; Lewens 2015).

Examples of concerns that may be excluded from ethical debates on new reproductive technologies are the opportunity costs of investing resources in research with genome editing, considering that people at risk of transmitting a harmful genetic mutation to their offspring could pursue alternative routes to fulfil their parenthood projects. The question of opportunity costs and alternative strategies is strictly interlinked with additional questions, which I discuss in Papers 3 and 4 and in the conclusions to Part II<sup>119</sup>. These questions pertain to the ethical standing of the preference to have genetically related children, to how far innovation

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<sup>118</sup> On this point, Jasanoff and Hurlbut (2018) argue: “If the ethical stakes of human germline genome editing are limited to questions of physical safety, for example, then the technical evaluation of particular biological endpoints (for instance, off-target effects) might offer sufficient answers. But such a focus short-circuits the central question of how to care for and value human life, individually, societally and in relation to other forms of life on Earth” (Jasanoff & Hurlbut 2018: 437).

<sup>119</sup> In Paper 3, I discuss the question of genetic relatedness with respect to genome editing, while in Paper 4 I discuss this question with respect to MRTs.

within reproductive medicine should be pushed and to how many resources should be deployed in order to satisfy this preference.

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Recently, the ethical standing of developing and allowing new reproductive technologies to satisfy the preference for genetic relatedness has been discussed within the context of MRTs, and indeed it has been used as a critique against these technologies by several commentators (Baylis 2017a; de Melo-Martín 2017b, Ch 8; Griffiths 2016; Petropanagos 2017; Rieder 2015a; Rulli 2016a, 2016b). For instance, Françoise Baylis (2017a), following Aristoteles' distinction of natural versus acquired desires, has argued that the preference for a genetically related child is comparable to the latter rather than the former, and that it can hence be regarded as a wish rather than as a need. According to her, this distinction casts doubts on the benefits of MRTs as their primary function would be to satisfy people's wishes rather than their needs and while there are good reasons to satisfy natural desires (needs), the same cannot be said for acquired desires (wishes). In Baylis' words:

[T]here are different kinds of wants with respect to the acquired desire to have a family that includes children, many of which can be met by existing, safe alternatives to human nuclear genome transfer [MRTs]. (Baylis 2017a: 14)

This is the view of other genetic-relatedness-sceptics, such as Tina Rulli (2016a, 2016b) and Travis Rieder (2015a). For instance, Rulli (2016a) has argued that the only real benefit of MRTs is that they allow women at risk of transmitting mtDNA diseases to their offspring to have children who are genetically related to them, which she sees as an unsatisfactory reason to implement these technologies. According to her, the preference to have genetically related children should not be satisfied at all costs, as:

[H]ard-nosed reality means we need more than preference—even deeply held preference—to justify our investment of medical dollars into developing a technology. We have more strong preferences than dollars available to satisfy them. (Rulli 2016a: 42)



Other concerns pertaining to MRTs and the preference for genetically related children are discussed in Paper 4 (Cavaliere & Palacios-González 2018). However, there is a difference between the two technologies and how the question of genetic relatedness applies to them. At present, one of the central questions with respect to genome editing is whether the preference for a genetically related child warrants the investment of the resources needed to conduct basic, pre-clinical, and clinical research, considering that PGD is an effective and reliable alternative in many cases (albeit not all; see, for instance, Vassena et al. 2016). With respect to the ethics of MRTs, again at present, the question of genetic relatedness does not only point, as Rulli (2016a) argues, in the direction of scarce resources and opportunity costs. MRTs have already been developed and implemented (at least in the U.K.). The question of genetic relatedness in this context hence points *also* towards whether criteria to access these technologies should be extended to other groups, especially in countries such as the U.K. where the safety and efficacy of these technologies has been thoroughly assessed by the HFEA and where they have been legally permitted. In addition, I am not convinced that arguing that genetic relatedness is a wish and not a need or that people should pursue alternative routes to parenthood is a conclusive argument against new reproductive technologies such as genome editing and MRTs. I return to the question of genetic relatedness and new reproductive technologies in Papers 3 and 4, and in the conclusion to this part of the thesis.

## 2 PAPER 3: Genome Editing and Assisted Reproduction: Curing Embryos, Society or Prospective Parents?

Paper 3 is a single-authored paper published in *Medicine, Health Care and Philosophy*.

The original version of this paper is enclosed in Appendix 3.

Cavaliere, G. (2018a). Genome editing and assisted reproduction: curing embryos, society or prospective parents?. *Medicine, Health Care and Philosophy*, 21(2), 215-225.

### 2.1 Abstract

This paper explores the ethics of introducing genome-editing technologies as a new reproductive option. In particular, it focuses on whether genome editing can be considered a morally valuable alternative to preimplantation genetic diagnosis (PGD). Two arguments against the use of genome editing in reproduction are analysed, namely safety concerns and germline modification. These arguments are then contrasted with arguments in favour of genome editing, in particular with the argument of the child's welfare and the argument of parental reproductive autonomy. In addition to these two arguments, genome editing could be considered as a worthy alternative to PGD as it may not be subjected to some of the moral critiques moved against this technology. Even if these arguments offer sound reasons in favour of introducing genome editing as a new reproductive option, I conclude that these benefits should be balanced against other considerations. More specifically, I maintain that concerns regarding the equality of access to assisted reproduction and the allocation of scarce resources should be addressed prior to the adoption of genome editing as a new reproductive option.

**Keywords:** Genome editing | Assisted reproduction | Genetic kinship | PGD | Therapy | Selection

## **2.2 Introduction: Genetic Diseases, Genome Editing and Existing Alternatives**

Different reproductive options are available for couples or individuals at risk of transmitting genetic diseases to their offspring who wish to have children. In this paper, I explore the ethical and social issues of introducing genome editing as a new reproductive technology and, in particular, as a potential replacement of preimplantation genetic diagnosis (PGD).

Some of the reproductive options available include refraining from having biologically related children and/or technologies to reduce or avoid the risk of transmission. The first set of options includes adopting existing children or turning to third-party reproduction (i.e. relying on a gamete donor). Adoption is currently legal in many European countries, but eligibility criteria vary. For instance, in some countries, access to this practice is limited to married heterosexual couples (e.g. Italy), while other countries have wider access criteria and allow same-sex couples (e.g. the Netherlands and the United Kingdom) and single parents (e.g. France and the United Kingdom) to adopt. In addition, other criteria such as marital status and age play a role in the decision to grant adoption.

Another possibility to avoid transmission of genetic diseases is for individuals to have partly genetically-related children and to seek gamete donors. This is commonly referred to as third-party reproduction, which allows couples to have children who are genetically related to a donor and to the unaffected individual in the couple. Third-party reproduction is currently only legal in some countries (e.g. the United Kingdom, the Netherlands and Spain) and usually restricted to heterosexual couples. Moreover, the state only subsidises IVF with donor gametes in a few countries (Gianaroli et al. 2016).

Alternatively, prospective parents at risk of transmitting genetic conditions to their offspring can seek to reproduce with assisted reproductive technologies (ARTs) that allow them to have genetically related children free from the condition that affects them (or one of them). Preimplantation genetic diagnosis (PGD) allows the testing of embryos created with IVF for genetic abnormalities prior to their transfer in utero. PGD is currently legal in many European countries (Gianaroli et al. 2016), while in others it remains restricted to so-called ‘serious’ conditions (e.g. in Italy and

Germany). It is completely banned in other countries (e.g. in Poland and Switzerland; Biondi 2013; Gianaroli et al. 2016). Across Europe, eligibility criteria vary. In the United Kingdom, for instance, the Human Fertilisation and Embryology Authority (HFEA) periodically revises and updates the lists of conditions that are eligible for screening with PGD. Other countries, such as Germany and Italy, recently approved the use of PGD, but access to this practice remains restricted to a very limited number of severe early onset conditions (Biondi 2013; Gianaroli et al. 2016).

Where PGD is legal, it is typically used in cases where both prospective parents are carriers of an autosomal recessive mutation. These mutations are responsible for the occurrence of autosomal recessive monogenic diseases (i.e. diseases caused by a mutation in a single gene) such as cystic fibrosis and sickle cells anaemia<sup>120</sup>. When both prospective parents are carriers of such mutations, future offspring have a 1 in 4 chance of inheriting the mutated gene and developing an autosomal recessive disease, while they have a 1 in 2 chance of inheriting one abnormal gene and thus becoming healthy carriers. PGD allows the testing and selection of embryos created through IVF to transfer in utero those that are either free from the abnormal gene related to the prospective parents' condition (or that are carriers of such mutated gene when no mutation-free embryo is obtained). PGD is also effective in cases where one of the prospective parents is heterozygous for an autosomal dominant mutation, meaning that they carry two different variants of a gene. Autosomal dominant mutations are responsible for the occurrence of diseases such as Huntington's and neurofibromatosis type 1. Future offspring have a 1 in 2 chance of developing autosomal dominant diseases even if only one of the prospective parents is affected, because it is possible that the embryo would carry the 'good' genetic variant from both parents. If the embryo inherited the disease-causing variant from only one parent, however, the resulting child would be affected by the disease.

It could be the case, that none of the embryos created through IVF is free from the undesirable genetic mutation. For instance, when one of the prospective parents is

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<sup>120</sup> Autosomal recessive diseases develop when an individual has two copies of an abnormal gene.

homozygous for a dominant genetic disorder, the risk of transmission to offspring is as high as 100%, and hence no mutation-free embryos can be obtained. In addition, when prospective parents are both heterozygous for a dominant genetic disorder, the risk of transmission is as high as 75%, hence the chances of finding mutation-free embryos significantly low. Another case where PGD is not effective is when both parents are homozygous for a recessive genetic disorder, meaning that they both carry two variants of the disease-causing gene (Nuffield Council on Bioethics 2016; Vassena et al. 2016). In such cases, genome editing could represent an alternative to PGD and a new reproductive option for some prospective parents: mutations potentially leading to monogenic diseases would be corrected in embryos created with IVF prior to the transfer in utero or directly onto prospective parents' gametes prior to fertilisation. Lastly, gene editing could replace PGD for women at risk of transmitting mitochondrial diseases as mitochondrial DNA mutations present in oocytes<sup>121</sup> could be corrected in the embryo (Vassena et al. 2016).

In the following paragraphs, I will briefly present the debate on genome editing technologies applied to human embryos and I will show how these technologies could be used as an alternative to PGD for the aforementioned cases where PGD is not effective. In section 2, I will present the moral reasons in favour of and against introducing genome editing as an alternative to PGD. In particular, I will present arguments in favour of using genome editing instead of, or as an alternative to, PGD, and argue that some of the moral arguments against PGD would not be applicable to genome editing. I will conclude, ad interim, that such arguments offer a *prima facie* case in favour of introducing genome editing as a new reproductive option, given that safety concerns are thoroughly assessed. In section 3, I will turn to other arguments on the ethics of introducing genome editing as a new reproductive option and argue that there are additional questions that need to be carefully addressed. I conclude that introducing genome editing as a new reproductive option would have

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<sup>121</sup> Currently, the United Kingdom is the only country that has allowed mitochondrial DNA replacement techniques. Such techniques represent the only existing method for couples where one member is affected by a mitochondrial condition to have genetically related children.

some benefits, but that concerns regarding the equality of access to assisted reproduction and the allocation of scarce resources should be addressed beforehand.

### 2.2.1 CRISPR and Assisted Reproduction

Gene-editing technologies have been around for over a decade. Zinc finger nucleases (ZFNs) and transcription activator-like effector nucleases (TALENs), two gene-editing technologies, were discovered in 2005 and 2010 respectively. ZFNs and TALENs are proteins that contain a module that can be engineered to recognise and target specific DNA sequences, and another module that can cut the targeted DNA sequence. These proteins are able to cause a double-strand break in the DNA, a break in two opposite sites of the two strands of the DNA molecule. These breaks are then repaired by the DNA's repairing machinery of the cell. ZFNs and TALENs are relatively precise techniques, but have the disadvantage that they need engineered proteins to target specific sequences of the DNA, a procedure that requires time and resources (Nuffield Council on Bioethics 2016).

A new gene editing technique sparked debate early in 2015 due to its application on non-viable human embryos by a group of Chinese scientists (Baltimore et al. 2015; Lanphier & Urnov 2015). The technique in question is CRISPR/Cas9, an RNA-guided tool composed of two parts: clustered regularly interspaced short palindromic repeat (CRISPR) and CRISPR-associated protein 9 (Cas9). CRISPR/Cas9 makes use of a naturally occurring defence mechanism that bacteria use to avoid harmful infections caused by pathogenic organisms (e.g. viruses). The RNA tool (CRISPR) functions as a guide for the Cas proteins to target specific parts of the genome, which are subsequently cut by the Cas proteins. These cut strands can be exploited to modify the nucleotide sequence of DNA and to insert genes at the cut site. The application of this technique to human embryos and human gametes (i.e. oocytes and sperm cells) has been widely criticised for a number of issues, but chiefly for its potential to introduce *inheritable changes* in the human genome (germline modification). Indeed, the issue of germline modification has catalysed the attention of many scientists and ethicists (Brokowski et al. 2015; Lander 2015; Lanphier et al. 2015).

This paper focuses on PGD and CRISPR<sup>122</sup> applications to the field of assisted reproduction. In particular, it focuses on CRISPR as a potential alternative to PGD. CRISPR could represent a tool to avoid the occurrence of genetic diseases in future children through the modification of the genetic makeup of embryos created with IVF from couples with a known risk of transmitting such genetic diseases. Since using CRISPR on early embryos could give to prospective parents who are either affected by monogenic diseases or who are carriers of them a chance to avoid the transmission of these diseases to their offspring, this particular application of CRISPR can be considered a new reproductive option for parents who want to have genetically related children.

### **2.3 Assisted Reproduction and PGD, or Assisted Reproduction and CRISPR?**

Research on human embryos with CRISPR technology is still at an early stage and only few experiments have been carried out thus far (Vassena et al. 2016). Despite this, the issue of allowing clinical research has been discussed recently (Gyngell et al. 2017; Reyes & Lanner 2017; Vassena et al. 2016;). The two main precautionary reasons that have been advanced against clinical applications of genome editing on human embryos or gamete cells are concerns regarding introducing changes in the human germline and safety questions. Many scholars and members of the public consider germline modifications unethical and a “line that should not be crossed” (Camporesi & Cavaliere 2016). The worry is that edited embryos will pass their edited genome on to future generations, thus introducing changes in humanity’s gene pool. While it is of fundamental moral importance to consider the impact of present actions that could potentially have an impact on future generations, it seems reductive to limit this precautionary reflection to changes introduced with genome editing technologies on reproductive cells and embryos. In particular, those who worry about germline modifications via CRISPR and other genome editing technologies maintain that there is something exceptional in changes introduced

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<sup>122</sup> The arguments made for CRISPR can be extended also to other future genome editing technologies. Throughout the paper, I will use CRISPR and genome editing or gene editing technologies interchangeably.

*technologically* in our genomes via genome editing (and indirectly into the genomes of our offspring). This view misrepresents partially the natural history of humankind and how past and present humanly introduced innovations shape future generations (Buchanan 2011). The introduction of agriculture, for instance, played a role not only in shaping our environment, but has fundamentally changed our genomes. The same could be said about technologies such as literacy and numeracy, which laid the foundations for technological innovations that have significantly changed us (Buchanan 2008, 2011). In other words, from a moral point of view, it seems irrelevant which *means* are used and whether inheritable changes are introduced with genome editing technologies or caused by other technological innovations, unless one is able to show the moral exceptionality of using genome editing technologies.

The other argument against allowing genome editing for clinical uses is concern for the safety of future offspring. At this stage, safety is indeed an issue and the efficiency of genome editing on embryos remains low, with mosaic embryos (i.e. embryos that have abnormal numbers of chromosomes in certain cells resulting in genetically different cells coexisting in the same organism) being the main known drawback of these technologies (Vassena et al. 2016). Despite this, some studies have proven the feasibility of gene editing in animals (Heo et al. 2015; Shao et al. 2014; Yoshimi et al. 2014; Zou et al., 2015), even though the efficiency of genetically modifying zygotes with Cas9 ranges between 0.5 and 40% (Araki & Ishii 2014). In addition, a recent study demonstrated the feasibility of preventing the onset of a genetic disorder such as cataract development (Wu et al. 2013) and the injection of Cas9 into primate zygotes led to the birth of genetically modified offspring (Liu et al. 2014; Niu et al. 2014).

### 2.3.1 The Case for Genome Editing: Two Sets of Arguments

There are two sets of arguments for introducing CRISPR and other gene editing technologies into the clinic, provided that safety concerns are properly addressed. In this section I first outline the first group of arguments, which concerns the benefits of genome editing for future children (and their children too) and for prospective parents (Gyngell et al. 2017; Reyes & Lanner 2017). In the following section, I



present additional reasons why genome editing could be a morally preferable alternative to PGD: genome editing would not be subjected to some of the critiques moved against PGD.

The moral reasons that ground the case for PGD (the welfare of future children and the reproductive autonomy of prospective parents. Pennings et al. 2007; Buchanan et al. 2001) can be extended to defend the clinical use of genome editing in reproduction. It is widely accepted that reproductive autonomy and respect for parental discretion in reproduction are values worth defending<sup>123</sup> (Buchanan et al. 2001; Robertson 1994). With respect to reproductive autonomy, genome editing would be comparatively better than PGD: it would offer an alternative to this technology for those aforementioned cases where PGD is not effective or for prospective parents who wish to increase their chances of having mutation-free embryos. In this sense, genome editing could be said to enhance reproductive autonomy. With respect to the welfare of the child, the case in favour of genome editing seems *prima facie* stronger than the case in favour of PGD. Unlike the latter technology, whereby embryos implanted can be carriers of the parents' mutated gene, genome editing would allow modification of the genetic makeup of embryos who would consequently develop into mutation-free offspring. In other words, genome editing would prevent the occurrence of genetic diseases in future generations, while PGD can sometimes only prevent the occurrence of genetic diseases in the child that develops from the implanted embryo (Gyngell et al. 2017).

There are, however, other arguments in favour of preferring genome editing to PGD. PGD is a contested practice as its scopes are not therapeutic (i.e. PGD does not *treat* embryos) but rather selective (i.e. PGD selects the embryos that should be transferred in utero. Asch & Barlevy 2012; Parens & Asch 2003). PGD as a means to select embryos that have a decreased risk of developing into a child with a genetic condition is seen as ethically troubling for two reasons: firstly, because it goes against the traditional ends of medicine and 'selects out' rather than 'cures' persons affected

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<sup>123</sup> At least when it is about medical conditions, but this is the case in question, so I will not enter into a discussion on so-called cosmetic traits and enhancement.

by genetic conditions (MacKellar & Bechtel 2014), and secondly, because decisions on which embryos should be selected are said to embody value judgements regarding people living with certain disabilities (Knoppers et al. 2006; Parens & Ash 2003), a critique of screening technologies that became known as the ‘expressivist argument’ or ‘expressivist objection’ (Buchanan 1996; Shakespeare 2006).

### 2.3.2 Selection *Versus* Therapy

PGD (at the moment) and CRISPR (potentially in the future) are two technologies that enable similar ends: in both cases, these technologies increase the chances of giving parents genetically related offspring unaffected by specific genetic conditions. Despite the similarity of the outcomes (i.e. healthy child), the means used are rather different. PGD is a form of genetic testing that allows screening for abnormalities in early embryos and to subsequently implant only those with a decreased risk of developing a certain condition. Instead, CRISPR and other gene editing technologies are tools for gene therapy that allow the modification of embryos or of gamete cells in order to avoid the occurrence of certain conditions in the future child (and in future generations).

Following this distinction of means, there is a sense that while PGD entails the *selection* of embryos, CRISPR is more akin to *therapy*. At this point, however, it is important to note that CRISPR and other genome editing technologies can be considered both therapeutic and non-strictly-therapeutic (or, following Wrigley et al., “pre-emptively therapeutic”; Wrigley et al. 2015: 636). I am not trying to violate Aristoteles’ principle of non-contradiction on the impossibility that contradictory assertions can be both true at the same time here. What I mean is rather that whether these technologies are therapeutic depends on what sort of factual and moral considerations are taken into account. If the focus is on the prospective parents, then CRISPR can be considered therapeutic in some instances because it could be used for those couples who have infertility-related issues. In this sense, it would represent a treatment for the couple’s infertility, which, following the 2009 definition of the WHO, can be considered a form of disease (Zegers-Hochschild et al. 2009).

If the focus is on the future children, we have two possible interpretations: following the view that equates embryos with persons, CRISPR *is* therapeutic because it treats the embryos (i.e. it treats persons), whereas PGD is selective because it selects in/out the embryos (i.e. it selects out persons). If, however, we are more inclined to think of embryos as beings with the *potential* to develop into persons (i.e. potentiality view, arguably a more widely shared position), then CRISPR is not straightforwardly therapeutic, because there is no person to be treated in the moment that we use the technology<sup>124</sup>. Despite this remark, I argue that there is a sense whereby genome editing can still be considered therapeutic, or, as mentioned above, pre-emptively therapeutic. Currently, ethicists and philosophers involved in the debate on reproductive genetic technologies seem to be divided on whether genome editing technologies applied to embryos are identity-affecting technologies or not, as this largely depends on the circumstances taken into account<sup>125</sup>. When I say “identity-affecting” I refer to the idea of numerical identity and to the metaphysical problem of determining how we can rightly refer to one and the same person in any different set of circumstances, despite the changes that the person undergoes over time. Thus, for instance, there is numerical identity between a person X and a person Y only if person X and Y are the same person. To put it simply, I am numerically identical to the person that is writing this paper at the

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<sup>124</sup> This observation is conditional as it relies on the interpretation of therapy as a practice that can only be defined as such if there is a *person* to be treated (Rulli 2017).

<sup>125</sup> I refer here to the debate on mitochondrial replacement techniques (MRTs) and not strictly on genome editing with CRISPR, as few commentators have dealt specifically with the question of whether genome editing is identity-affecting (for two examples, see: Gyngell et al. 2017; Liao 2017). One of the two techniques for the replacement of faulty mitochondrial DNA, pronuclear transfer (PNT), arguably represents the most similar case to genome editing as, unlike the other technique for the replacement of mitochondrial DNA (maternal spindle transfer –MST), it is applied after the oocytes has been fertilised. The contention, in the case of PNT, is whether this technique is identity-affecting or not, and commentators have presented differing views on this matter (Liao 2017; Palacio-González 2017; Rulli 2017; Wrigley et al. 2015). While I am aware that PNT and CRISPR are two distinct technologies, PNT arguably represents the most similar case to genome editing as both CRISPR and PNT are applied *after* fertilisation. Hence, other things being equal, arguments concerning whether PNT is identity-affecting or not can also be considered valid in discussions on whether CRISPR is identity-affecting. It must be noted however, that those who explicitly referred to genome editing maintained that it is *not* identity-affecting (Gyngell et al. 2017; Liao 2017). Interestingly, authors who speculatively consider the possibility of using gene therapy on human embryos before the availability of CRISPR are also divided on this issue (Buchanan 1996; McMahan 2006; Sparrow 2008).

moment. The challenge of any account of numerical identity is then to explain what determines the entity that we in fact are despite the changes that we undergo over time. In this sense, if I grow taller or if I lose an eye due to an accident, I am still numerically identical to the entity I was before having that accident or when I was shorter. This is the case because changes such as losing an eye or growing taller are largely considered *contingent* to numerical identity, namely they do not change the entity that I am.

Returning to genome editing, those who do not subscribe to the embryos as persons view can view the technology in two different ways. The contentious matter is whether applying CRISPR on embryo X creates a numerically different entity (call it embryo Z, that will eventually develop into person Z) or it just leads to a numerically identical entity (call it embryo X\*, that will eventually develop into person X\*) in the same sense that applying gene therapy on adult X does not create a different adult Z, but only leads to a numerically identical adult X\*. While in the first case genome editing would be considered an identity-affecting technology (i.e. a technology that by virtue of its use creates an entirely new entity), in the second case it would amount to a non-identity-affecting technology<sup>126</sup>. Following the first interpretation, CRISPR cannot be considered a therapy as, by virtue of its use on an embryo, it determines the kind of person that is brought into being rather than pre-emptively curing the same pre-person. On the contrary, if we are inclined to

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<sup>126</sup> Despite some challenges, the biological origin (or gametic origin) that a person has is widely considered a necessary condition of what determines the human being that we are. This is well explained by philosopher Derek Parfit's 'Origin View' (or gametic essentialism): "each person has this necessary property: that of having grown from the particular pair of cells from which this person in fact grew" (Parfit 1984: 353). In other words, the fact that two gametes came together and generated me is, under this view, considered a necessary condition of my identity: I am the entity that I am by virtue of my gametic origin. Now, this is linked to the discussion of treatment and selection because a technology such as PGD is identity-affecting. In other words, using PGD causes a numerically different person to come into being, namely a different person than the person that would have come into being had PGD not been used. In the case of genome editing, since the intervention takes place *after* fertilisation, the gametic origin of the genetically modified embryo and the gametic origin of the non-genetically modified embryos are identical. In other words, these two embryos are numerically identical. The contention, however, is that gametic origin is only a necessary and not sufficient condition for having a specific identity. Thus, whether genome editing technologies applied to zygotes/embryos cause a different person to come into being or not remains an open question. If they do, then such technologies cannot be considered therapeutic because a different person comes into being due to the use of genome editing. If they do not, they can be considered therapeutic.

follow the second interpretation, then CRISPR is therapeutic as it pre-emptively cures an embryo that will develop into a numerically identical child that does not have the genetic condition that is consciously avoided<sup>127</sup>. It is only in this second sense that it is possible to say that if the genome of an embryo affected by a certain genetic condition is modified and this condition eradicated, then this embryo will develop into a numerically identical child who, had CRISPR not been used, would have been affected by a genetic disease. As a consequence, even if one does not subscribe to the embryo-as-persons view, *there is a sense* whereby genome editing can be considered at least *more similar* to therapy than to selection: genome editing would be a pre-emptive treatment for the genetic disease that is caused by the genetic mutation at the embryonic stage.

If the second interpretation about genome editing being non-identity-affecting is embraced, then both the teleological objection (i.e. PGD is morally problematic because it does not fall within the traditional ends of medicine) and the selective attitudes objection (i.e. PGD is morally problematic because it promotes selective and discriminatory attitudes) seem to be less applicable to the use of genome editing on embryos to prevent the occurrence of certain conditions in future children. As explained above, editing the genome of embryos can be considered pre-emptively therapeutic and thus falls within (or at least closer to) the traditional ends of medicine. From this, it also follows that it would be problematic to consider such practice as selective or discriminatory: disability scholars would have to condemn all the interventions aimed at treating genetic diseases (Barnes 2014).

These clarifications have normative implications, namely that, once the safety of editing the genome of human embryos is carefully assessed, the latter technology should be considered preferable to PGD. In the next section, I will outline some

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<sup>127</sup> If genome editing is employed before the 14<sup>th</sup> day after fertilisation (as it is required by embryos research regulations in the United Kingdom and in many other countries, Hyun et al. 2016), the embryo could still cleave into two (i.e. twinning). In this case, the children that could potentially develop from such embryo will be two. However, twinning occurs spontaneously and it is not influenced by the use of genome editing on the embryo. As a consequence, the use of the technique does not directly affect the numerical identity of the future child/children as it is not the direct causation of the embryo splitting.

additional questions that need to be addressed and explain why preferring CRISPR over PGD is not completely cost-free.

#### 2.4 Curing Embryos, Society or Prospective Parents?

In the previous sections, two main questions have remained unaddressed. One question is on the value and meaning of genetic parenthood. Another, albeit related, question concerns the ethics of existing alternatives. I explore these two questions in this last section and conclude that they provide at least some *prima facie* moral reasons for carefully considering the introduction of a new reproductive option when similar options are already available.

A peculiar feature of assisted reproductive technologies such as PGD, and possibly genome editing, is that they are often offered to prospective parents who are affected by a genetic condition in order to conceive (or increase their chances of conceiving) healthy offspring. It is in this sense that these technologies represent a *solution* for those prospective parents whose *problem* is the impossibility of having a *genetically related* and *healthy* child; or at least healthier than the child that would otherwise be brought into the world had these technologies not be employed. As explained in the first section of this paper, there are other options than PGD to increase the chances of having healthy children, but they entail refraining from having biologically related children (for one individual in the couple or, in the case of adoption, both parties). Reproductive technologies such as PGD and genome editing convey the interests of different groups: the prospective parents, the future offspring and the society where these offspring will grow and thrive. Despite the importance of all three stakeholders, their interests are not granted equal importance: the welfare of future children and the reproductive autonomy of the prospective parents are usually considered of greater moral importance than the aggregate interests of society in having healthy members, respecting competing values on assisted reproduction, and limiting the use of certain technologies against a backdrop of scarce resources. This is what I define as the received view on the ethics of assisted reproductive technologies. An ethical assessment of whether

introducing new technologies in the context of reproduction should thus consider these three aspects (with the aforementioned prioritisation in mind) in turn.

#### **2.4.1 Reproductive Autonomy, Child Welfare and the Interests of Society**

Genome editing, at first sight, seems to score high on the reproductive autonomy and welfare of the child fronts: unlike PGD, it allows for more conditions to be corrected and the reduction of the occurrence of certain genetic conditions in future generations; it also increases the reproductive autonomy of the parents by offering not only one more possibility in the geneticists tool-box, but also by allowing those couples for whom PGD is not always successful to have biologically related, healthy offspring. So far so good. Or maybe not? The idea that more choice leads to greater freedom has been challenged (Dworkin 1982; Rose 1999; Rothman 1985). More options can also translate into more uncertainties, and greater perceived and actual responsibilities for the prospective parents (Dworkin 1982). In this sense, introducing genome editing into the clinic as an alternative to PGD may be detrimental for the very same prospective parents that it is designed for. While genome editing may be more routinely employed in the future, some issues will likely remain. These issues include, for instance, reflections upon which conditions should be eligible for the use of genome editing and whether parents who fail to employ the most efficient technology available could be considered morally responsible (Rothman 1985).

What about the welfare of the future child? The empirical question of whether safety concerns will be put to rest and genome editing will ever be safe enough to represent a concrete alternative to PGD divides scholars. The reasons for this are twofold: first, no one knows the answer to such questions *yet*. Secondly, this empirical question is strongly influenced by the value judgements of scientists, ethicists, policy-makers and the public on the degree of certainty required to move forward. Hence, even without denying that such empirical questions will be eventually be put to rest, it is still important to note that a consensus on the question of safety will be hard to reach due to the competing values at stake in stakeholders' assessments. Those taking a precautionary stance concerning technological development will favour existing technologies over the newly discovered, while

those who are generally in favour of technological development will be ready to accept a higher degree of risk in the name of such progress and of the potential benefits that it may yield. With respect to the safety and the welfare of the future child, whether genome editing really represents a better option than PGD will thus divide scholars, scientists and the public (and, as exemplified by the debate on embryo-applications of CRISPR, already does). A decision on whether to allow genome editing will thus have to rest not only on a thorough assessment of the safety of the techniques, but also on a democratic process that takes into account such differing views and values (Jasanoff et al. 2015; Kitcher 2001). The ethical assessment of new techniques ought to not only rest on a cost/benefit analysis, but also on an evaluation of existing alternatives, including those that do not rely on biomedical means. In other words, whether genome editing really represents a worthy alternative to existing options (such as PGD) depends on the extent to which the welfare of the future child can be put at risk to allow couples to have a genetically related child. Regulators and ethicists that argue in favour of eventually replacing PGD with genome editing, and couples for whom PGD does not represent an option, will have to consider whether reproductive autonomy should trump questions on the welfare of the child in light of uncertainty.

Lastly, what role should societal interests and views play in the decision over whether genome editing should replace PGD? There are historical reasons why some interventions of society or the state in reproductive choices are looked at with suspicion, and the shadow of eugenics seems to extend over any discussion regarding reproductive technologies and their governance (Paul 1992). Despite these worries, the regulation of new reproductive technologies will be influenced by governments' policies and the interests of society will likely play a role in these decisions. There are two main ways in which the interests of society might play a role in the decisions on whether to allow genome editing technologies and whether they represent a valuable alternative to PGD. The first is whether genome editing is ethically acceptable for a large segment of society (Kitcher 2001), and second, related, is whether existing alternatives warrant the introduction of a new practice and the clinical research necessary to safely implement it. Almost every new technology introduced or discussed for potential introduction in reproduction seems to stir



controversies. The recent debates on genome editing (Camporesi & Cavaliere 2016), mitochondrial replacement techniques (Appleby 2015) and ‘older’ debates on PGD (Scott 2006) are just a few instances of these controversies. However, once certain uses are constrained and lines drawn (for instance between therapeutic and enhancing uses), these technologies have been approved and, at least in certain countries, accepted by large swaths of the population. Thus, even if genome editing will be met with controversies and will encounter resistance, it does not *prima facie* translate into the need for banning any research involving it. On the contrary, this should translate into support for a democratic and deliberative approach to the governance of technological innovation (Jasanoff et al. 2015) and into the respecting of competing moral views on these issues.

#### **2.4.2 The Hidden Costs of Introducing Genome Editing as a New Reproductive Option**

At this point, there is, however, there is one last thing to consider: while it is true that genome editing could open up new reproductive possibilities for certain couples (i.e. enhance reproductive autonomy) and provide heritable benefits to their future offspring (i.e. considerations regarding the welfare of future child), these benefits ought to be balanced against the costs of introducing a new reproductive technology. These costs include the investment of public resources, considering both the scarcity of such resources and the existence of available alternatives. Emanuel et al. (2000) argue that for clinical research to be ethical, among other requirements, it needs to have social value, namely it should be directed at “a diagnostic and therapeutic intervention that could lead to improvements in health and well-being” (Emanuel et al. 2000). Being of social value is an ethical requirement for clinical research to go forward precisely because it operates in a context of scarce resources. From this it follows that if the social value of a technology is limited, then the investment of public resources for the development and implementation of such technology may be unethical (Rulli 2016a). The proposed clinical research (in this case that needed in order to implement genome editing as an alternative to PGD) needs to be evaluated on two levels: absolute and relative. The absolute level is

settled once the proposed research is expected to bring about improvements to health and well-being. The relative level, however, needs more: the proposed research (and the improvements to health and well-being thereof) needs to be compared both with other potential uses of those scarce resources and with existing alternatives to bring about similar improvements to health and well-being. Two of the criteria that are often employed to assess whether to invest resources in certain clinical research and whether it will bring about significant improvements to health and well-being are the severity of the condition and the number of individuals that it affects (Rulli 2016a). If we consider these two criteria, the benefits of the introduction of genome editing as a new reproductive option are arguably minor and thus may not warrant the investment of public resources. The number of cases for which PGD is not an option, as mentioned in the first section, is limited. In addition, considering the importance of taking into account future children's welfare, the unresolved questions concerning safety seem to indicate that health improvements may not be so significant. An obvious critique to this is the following: clinical research is aimed at improving techniques in order to achieve significant benefits for future children. This is certainly correct and we would not enjoy the benefits of many technologies and drugs if it was not for clinical research. But again: resources are limited and not all research can be publicly funded.

Returning to the relative level to evaluate clinical research, it is important to consider that improvements in the health and well-being of future children can also be achieved by looking at alternative solutions, for instance third party reproduction or adoption. For those limited number of parents for whom PGD is not an option, the choice is not between genome editing and a sick child. The choice is much wider than that. This does not mean that the choice of adopting or relying on third party reproduction comes without a cost, or that prospective parents' wishes should be neglected. It only means that there are other interests at stake and that there are other strategies than developing new technologies to tackle health needs.

These considerations do not lead to the conclusion that public interest (in the form of a prudent use of resources) should be prioritised over prospective parents' reproductive autonomy and future offspring's welfare. On the contrary, the received

view, namely the view that considers the interests of these two groups as more morally relevant than those of society, ought to be taken as the default position. But this position should not prevent us from seeking alternatives. Perfecting existing technologies such as PGD, and possibly widening the criteria of access to adoption or third party reproduction, would be a less costly and possibly quicker strategy to grant future children's welfare while at the same time respecting prospective parents' wishes. Making existing technologies and practices available via broader state funding schemes would allow their use by larger swaths of the population.

### 2.5 Conclusions: Context Matters

In this paper, I have analysed the moral case for introducing genome editing as an alternative to PGD. I have presented the reasons in favour and the two main arguments against this possibility, namely safety and germline modifications. After presenting some of the available data on the safety of CRISPR, I have argued that concerns with germline modifications do not represent a compelling argument against the introduction of genome editing into the clinic. I have then turned to arguments in favour of genome editing and concluded that there seems to be a *prima facie* case in favour of starting clinical research with CRISPR. In the last section, I have focused on the moral reasons that are normally taken into account in debates on reproductive technologies, namely the welfare of future children, the reproductive autonomy of the parents and the interests of society. I have showed that a closer look at genome editing in light of these moral reasons seems to generate some additional reasons for caution in accepting genome editing as a new reproductive option. These reasons may entail shifting from funding new resources, such as CRISPR, and advocating for its introduction in the name of values such as reproductive autonomy and the welfare of future children, to focusing on widening the criteria of access to existing options and possibly re-thinking resource allocation and state funding of assisted reproduction. This paper does not attempt to provide decisive arguments in favour of or against the introduction of CRISPR as a new reproductive option. As many have argued, it may be too soon to have a conclusive assessment of this possibility, if only for the dearth of empirical data regarding its

safety and feasibility. Rather, this paper offers a basis to begin a discussion on the ethics of introducing genome editing as an alternative to PGD and stresses the need to consider that scientific research does not happen in a vacuum where the soundest theoretical argument wins. Rather, it happens in a context where resources are limited, where genetic parenthood is an important value cherished by many, and where technical solutions are often given preference over other strategies.

#### 2.6 Declaration

**Competing interests** The author declares that she has no competing interests.

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### 3 PAPER 4: Lesbian Motherhood and Mitochondrial Replacement Techniques: Reproductive Freedom and Genetic Kinship

Paper 4 is a co-authored paper (with César Palacios-González) published in the *Journal of Medical Ethics*.

The original version of this paper is enclosed in Appendix 4.

Cavaliere, G., & Palacios-González, C. (2018). Lesbian motherhood and mitochondrial replacement techniques: reproductive freedom and genetic kinship. *Journal of Medical Ethics*. Published Online First: 28 February 2018, doi: 10.1136/medethics-2017-104450

Statement of contribution: I am the first author of this paper. I conceived the idea of discussing under what conditions lesbian couples could be granted access to MRTs and the role of reproductive freedom in addressing this question. CPG contributed to the paper by providing arguments to show that MRTs are not therapeutic technologies and that they cannot be said to harm future children. I wrote the first drafts of the sections on reproductive freedom and genetic relatedness. CPG wrote the first drafts of the sections on mtDNA diseases and MRTs, and whether MRTs can be considered therapeutic. Both CPG and I then reviewed each other's sections several times and revised the paper according to the reviewers' comments.

#### 3.1 Abstract

In this paper, we argue that lesbian couples who wish to have children who are genetically related to both of them should be allowed access to mitochondrial replacement techniques (MRTs). Firstly, we provide a brief explanation of mitochondrial diseases and MRTs. We then present the reasons why MRTs are not, by nature, therapeutic. The upshot of the view that MRTs are non-therapeutic techniques is that their therapeutic potential cannot be invoked for restricting their

use only to those cases where a mitochondrial DNA (mtDNA) disease could be ‘cured’. We then argue that a positive case for MRTs is justified by an appeal to reproductive freedom, and that the criteria to access these techniques should hence be extended to include lesbian couples who wish to share genetic parenthood. Finally, we consider a potential objection to our argument: that the desire to have genetically related kin is not a morally sufficient reason to allow lesbian couples to access MRTs.

### 3.2 Introduction

One of the main purposes of bioethics is to demarcate morally acceptable applications of biomedical technologies. For example, in the past decade there has been much debate in the field on whether there is a morally significant difference between therapeutic and enhancing genetic modifying interventions. ‘Bioconservatives’ such as Michael Sandel (2007) and Jürgen Habermas (2003) maintain that biotechnological practices aimed at curing disease are morally acceptable, whereas those aimed at increasing certain traits such as height and strength are morally suspicious. Other moral boundaries investigated by bioethicists concern morally appropriate versus inappropriate uses of reproductive screening technologies – such as preimplantation genetic diagnosis (PGD) – and of rerogenetics technologies – of which mitochondrial replacement techniques (MRTs)<sup>128</sup> are an example. These techniques help women wishing to become mothers who carry mitochondrial DNA abnormalities in their eggs to have genetically related offspring free from mitochondrial DNA (mtDNA) diseases (Vogel & Stokstad 2017).

MRTs have been at the forefront of bioethical debate since the U.K. began to discuss their legalisation in the 2000s. In February 2015, regulations were passed on two MRTs: maternal spindle transfer (MST) and pronuclear transfer (PNT). These

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<sup>128</sup> Even though the name ‘mitochondrial replacement techniques’ is contested here, we use it because it has secured a foothold within the academic debate; see Palacios-González (2016). Ainsley Newson and Anthony Wrigley (2017) have recently proposed and defended the term ‘mitochondrial targeting techniques’ (Newson & Wrigley 2017).

regulations came into force in October 2015, making the UK the first country in the world to explicitly legalise MRTs under a licensed scheme (Human Fertilisation and Embryology 2015)<sup>129</sup>.

Although these technologies are legal in the UK, at the present time only people at risk of transmitting a severe mtDNA disease can access them. The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 state that the permitted circumstances for using these techniques are when:

There is a particular risk that any egg extracted from the ovaries of a woman named in the determination – or embryo which is created by the fertilisation of an egg extracted from the ovaries of a woman named in the determination – may have mitochondrial abnormalities caused by mitochondrial DNA; and there is a significant risk that a person with those abnormalities will have or develop serious mitochondrial disease. (Human Fertilisation and Embryology 2015)

Part of the rationale for these regulations is to allow couples at risk of transmitting mtDNA diseases to have children who are free from them (Scott & Wilkinson 2017). In addition, MRTs may aid lesbian couples, and couples where both members have functional ovaries (i.e. couples or relationships where one member may be intersex or transgender) to have genetically related children<sup>130</sup>. It has also been theorised that they can be used to increase the chances of avoiding embryonic arrest and thus allow couples whose infertility is not related to mtDNA mutations to have genetically related children too, but *this possibility awaits empirical demonstration*<sup>131</sup>. These two potential applications of MRTs are not at present legal in the UK. However, it must be said that it seems that the MRTs regulations were not written down with the explicit intention of singling out these possibilities as illegal but rather

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<sup>129</sup> Interestingly, the first couple of babies born because of MRTs were not born in the UK, but in the United States (by means of maternal spindle transfer) and Ukraine (by means of pronuclear transfer) (Coghlan 2016; Hamzelou 2016).

<sup>130</sup> Even when in this paper we mainly refer to lesbian couples, our arguments equally apply to all couples where both members have functional ovaries or cryopreserved eggs.

<sup>131</sup> Due to space constraints here we do not investigate, or focus on, the ethical aspects of offering MRTs to heterosexual couples with non-mtDNA-related infertility problems. We also do not discuss other ethical issues related to MRTs more generally, such as risks to egg providers.

in the attempt to make MRTs legal in order to avoid mtDNA diseases (Scott & Wilkinson 2017).

Legal scholars, bioethicists and stakeholders participating in the debate on MRTs have tried to establish a morally significant boundary between acceptable and unacceptable applications of these techniques. For example, the mitochondrial disease community (patients, researchers and clinicians) have strongly advocated for a therapeutic (i.e. acceptable) and a non-therapeutic (i.e. unacceptable) demarcation of MRTs. By doing so they aim, in part, to avoid challenges from slippery-slope type arguments that allowing MRTs would then lead to ‘designer babies’.

In this paper, we argue that lesbian couples who want to have children who are genetically related to both of them should be allowed access to MRTs. The paper is structured as follows. Firstly, we provide a brief explanation of mitochondrial diseases and MRTs. Secondly, we show that MRTs are not therapeutic in nature and thus this feature of the techniques cannot be invoked for restricting their use only to those cases where an mtDNA disease could be ‘cured’. We then argue that a positive case for MRTs is justified by an appeal to reproductive freedom and that access to these techniques should hence be extended to lesbian couples. Finally, we consider a potential objection to our argument: namely that the desire to have genetically related kin is not a morally sufficient reason to allow lesbian couples to access MRTs.

### **3.3 Mitochondrial Diseases and MRTs**

Mitochondria have been described as the ‘powerhouses’ of our cells. They are small structures whose main known purpose is to produce the necessary energy for cellular, organ and bodily function (Tachibana et al. 2009). They are inherited via the maternal line and have their own DNA (mtDNA), which resides outside the cells’ nucleus. Mitochondrial diseases are a cluster of neuromuscular diseases which symptoms vary in severity and expression and can develop immediately after birth or later in life (Bredenoord & Braude 2010; Reinhardt et al. 2013). Mutations both in the nuclear DNA and the mtDNA can cause mitochondrial diseases. Deleterious mutations in the mtDNA, in each cell, can happen across all mitochondria (this is



known as homoplasmy), or they can occur only in certain mitochondria (known as heteroplasmy). In this paper, we will only discuss mitochondrial diseases produced by problems in the mtDNA, referred to as mtDNA diseases.

To avoid the transmission of an mtDNA disease, two MRTS have been developed: pronuclear transfer (PNT) and maternal spindle transfer (MST). PNT requires the creation of two zygotes, through assisted reproductive techniques, one with the gametes of the intending parents (or intending mother and a sperm donor) and the other with a donated egg and the intending father's (or donor's) sperm. In this scenario, the first zygote has faulty mitochondria and the second has healthy mitochondria. On the first day after fertilisation, the maternal and paternal pronuclei are removed from both zygotes. The enucleated cell produced with the intending mother's egg and the pronuclei which were housed in the cell produced with the donor's egg are discarded. Afterwards, the intending parents' (or intending mother's and donor's) pronuclei are ferried into the enucleated cell produced with the donor's egg. The reconstructed zygote, which possesses healthy mitochondria, can be transferred to the intending mother or a surrogate (Craven et al. 2010).

In MST, eggs are obtained through assisted reproductive techniques from an intending mother and a healthy donor. The nuclear material from the intending mother's egg and the donor's egg is extracted. The donor's nuclear material and the intending mother's enucleated egg are discarded, and the intending mother's nuclear material is ferried into the now enucleated donor's egg <sup>132</sup>. Subsequently, the reconstructed egg is fertilised *in vitro* and then transferred to the intending mother or a surrogate (Tachibana et al. 2009). The aim of both techniques is for the donor's healthy mitochondria to help in the development of a healthy child and to be passed down via the maternal line to subsequent generations.

At present, approximately 30 mtDNA haplogroups in humans have been described (van Oven & Kayser 2009). The fact that there are so many groups is important for

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<sup>132</sup> Both for PNT and MST, if during the chromosomal transfer there is a large unintentional carryover of pathological mitochondria the mtDNA disease could manifest immediately afterwards and in subsequent generations (Hyslop et al. 2016; Yamada et al. 2016).

our discussion, as there is an ongoing debate regarding mito-nuclear interactions after MRTs. Some, for example Edward Morrow, argue that if the mitochondrial haplogroup of the egg donor is not matched to that of the intending mother this could give rise to mito-nuclear incompatibility, translating into adverse health effects for the future offspring (Reinhardt et al. 2013). The last report commissioned by the Human Fertilisation and Embryology Authority (HFEA) concerning MRTs being ready for clinical practice asserted that:

The panel continues to recommend that consideration is given to mtDNA haplogroup matching as a precautionary step in the process of selecting donors (...) At present, the panel believes any risks associated with a mtDNA-nuclear DNA mismatch remain theoretical; the recent studies examining embryonic cells and stem cells generated from MST- and PNT-derived human embryos reported no evidence of any complications or compromise of mitochondrial function arising from unmatched mtDNA haplogroups. (Greenfield 2016)

Prior to the advent of MRTs, women at risk of transmitting an mtDNA disease who knew about their condition had the following options: firstly, refraining from having children; secondly, turning to adoption, embryo adoption or gamete donation; thirdly, seeking to have genetically related children after undergoing oocyte sampling to assess the risk of recurrence (for couples who have already had an affected child), or chorionic villus sampling or amniocentesis (and then deciding for or against termination), or by using preimplantation genetic diagnosis (PGD). It must be noted that while adoption, embryo adoption and gamete donation guarantees that future children will not be affected by an mtDNA disease, PGD and the other techniques do not always guarantee similar results (Poulton et al. 2009). In the specific case of PGD, when the mutations are novel or uncommon there is not enough reference clinical data available to guide the couple's decision (Poulton et al. 2009).

Different reproductive options are currently available for lesbian couples (de Wert et al. 2014). Some of them, such as adoption, embryo adoption and gamete donation, entail either refraining from having genetically related children (adoption and embryo adoption) or having children that are genetically related to only one of the couple (third-party reproduction). Recently, another possibility, ROPA (reception

of oocytes from partner), has gained some visibility (Marina et al. 2010; Zeiler & Malmquist 2014). ROPA allows lesbian couples to have a child who is genetically related to one mother (i.e. the mother who provides the oocytes which are subsequently fertilised with donor sperm) and who is gestationally related to the other mother. These options *do not allow* lesbian couples to have children who are genetically related to *both* of them<sup>133</sup>. MRTs, on other hand, would allow both women in a lesbian couple to share a genetic link with their offspring. Specifically, one of them would contribute with nuclear DNA and the other with mtDNA. Finally, it is important to mention that worldwide reproductive options for lesbian couples (and homosexual couples more generally) are often directly or indirectly limited by laws and regulations which restrict access to adoption and third-party reproduction.

### 3.4 Are MRTs Therapeutic in Nature?

Debates on the ethics of reprogenetics technologies stir controversies as they touch upon values and beliefs on the meaning of parenthood, the moral status of early human life and our obligations to future generations. In particular, debates on the ethics of introducing a new reproductive technology are characterised by reflections on the welfare of children born due to that technology. They are centred on the necessity of balancing uncertainties regarding the possible benefits and risks of such new technology and on the extent to which the reproductive freedom of prospective parents ought to be respected (Cavaliere 2018a). Even though competing moral views generate diverging assessments of the importance that should be granted to the values and beliefs at stake, concerns related to the welfare of future children are often considered more important than the reproductive autonomy of prospective

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<sup>133</sup> Even when it is true that there are epigenetic influences during pregnancy and that the gestating mother could be thought to have genetic ties to the child she bears, here we are using ‘genetic’ in a more narrow sense. We understand ‘genes’ as physical tokens of transmission that originate in the parent and that could be said to materially overlap between parent and child. We appreciate that there are many and important philosophical questions regarding the role of epigenetic influence in parenthood, but they are beyond the scope of this paper. We are indebted to one of the anonymous reviewers for pointing this out to us.

parents. This is so as preventing a child (albeit a future one) from suffering harm is considered a morally appropriate reason to restrict prospective parents' freedom.

Unsurprisingly, the debate on MRTs is no exception and welfare of the child considerations have been at the forefront of the ethical debate concerning these techniques. Interestingly, the welfare of children born due to MRTs has been employed *both as a critique of these techniques and as an argument in favour of them*. For instance, those who use the welfare of the future child to oppose MRTs maintain that these techniques are too risky for the health of future children, that their safety has not been thoroughly assessed, and that there may be unforeseen negative effects not only for the children conceived due to MRTs but also for these children's children (Baylis 2013; Baylis 2017a; de Melo-Martín 2017a, 2017b; Morrow 2014; Newman 2013) For example, Françoise Baylis (2013) asserts that:

Mitochondrial replacement technology is experimental and there is very limited information about safety and efficacy. As with any germline intervention, there are significant and legitimate concerns about the health and wellbeing of future children and the potential short- and long-term harms to them and their progeny. (Baylis 2013: 533)

According to this view, a concern for the welfare of future children (and those children's children) warrants banning or heavily restricting MRTs until all the above-mentioned worries have been dispelled. Interestingly, many of those in favour of the techniques have also appealed to welfare of the child considerations and maintain that it is such concerns which should motivate their approval, albeit their take on the present safety of the techniques is radically different (Caplan 2015; Harris 2016a; Johnson 2013; Wrigley et al. 2015). According to such commentators, the severity of certain mtDNA conditions and their disabling and life-limiting character are sufficient reasons to allow for the clinical use of MRTs. For example, Arthur Caplan argues that an MRT procedure "is not without its risks, but it's treating a disease" (Smith 2017). And that:

These little embryos, these are people born with a disease, they can't make power. You're giving them a new battery. That's a therapy (Smith 2017)

Framed in this way, it is clear that MRTs can be regarded as a therapy for mtDNA diseases.

The argument in favour of MRTs based on their ‘therapeutic’ nature is a powerful one: who would dare object to the approval of safe techniques that spare children from suffering? This argument runs something like this: we are morally required to prevent the suffering and premature death of innocent individuals. MRTs can prevent the suffering and premature death of existing innocent individuals. Hence, we are morally required to carry out MRTs.

The framing of MRTs in terms of a therapy for mtDNA diseases for existing individuals (in contrast with future ones) allows supporters of these techniques to build a moral case in favour of their approval, and, at the same time, to raise a supposedly justified moral boundary. The moral line is drawn between uses that are therapeutic and hence good, and uses that are ‘beyond therapy’ and thus morally suspicious. In order to make our case that lesbian couples should have access to MRTs to have genetically related children we first challenge their alleged therapeutic nature. Doing so allows us to show the therapeutic / non-therapeutic moral boundary does not exist and thus that criteria of access to MRTs must be grounded on other considerations.

Thus far, Wrigley et al. (2015) have carried out the most thorough defence of the therapeutic nature of MRTs (or at least of one of the two techniques). The authors maintain that “PNT [...] is a form of therapy based on embryo modification while MST is, instead, an instance of selective reproduction” (Wrigley et al. 2015: 631). They draw this conclusion from the fact that the process of PNT (which entails enucleation, transfer and reconstitution) does not affect the numerical identity of the embryo as it already exists. PNT pre-emptively cures an already existing being. Conversely, at the point of the process of MST (which also entails enucleation, transfer and reconstitution) it is unknown (in almost all cases) which *sperm cell* will fertilise the reconstituted oocyte, and thus the identity of the future individual has not been determined (supposing that our numerical identity is determined by specific gametes which fuse). On this basis, Wrigley et al. (2015) conclude that MST cannot cure anyone while PNT does. The upshot of their argument is that there is:

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[A] strong prima facie harm-avoidance rationale for *offering* PNT to prospective parents, and for those parents to accept it; one that is not present in the case of MST ([emphasis added] Wrigley et al. 2015: 636)

Wrigley et al.'s stance has been criticised for a number of reasons (Palacios-González 2017a; Rulli 2017). One point of contention is that there is no harm-avoidance rationale *for offering PNT* to prospective parents, as at the point of offering it there is no-one who could be subject to PNT, and thus no-one who could be cured. When *the clinical decision to employ* PNT is made it affects which sperm and egg will fuse, which means that:

[T]he gametes that will fuse in order for the process of PNT to happen *would most certainly not have fused* in the first place if PNT had not been chosen as the course of action. (Palacios-González 2017a)

This is the case because after the decision to carry out PNT has been made, the woman will have to be subject to hormonal stimulation and to the egg extraction process. This means that the egg that would have been fertilised the month that she/the couple decided to undergo PNT is not the same egg as that which will be fertilised prior to undergoing the PNT procedure. And even in the rare case of having only one single cryopreserved egg, the sperm cell that will fertilise the egg will depend on when the sperm sample is provided, or which sperm from an already collected sample is actively chosen, or which sperm happens to fertilise the egg *in vitro* from an already collected sample. All this shows that *the clinical decision to employ* PNT affects the timing of conception and thus who will exist.

Additionally, Matthew Liao (2017) has argued from an Organism View account that *the process of MST and PNT* is numerically identity-affecting (Liao 2017). According to Liao (2017), the enucleation, transfer and reconstitution actions are of such nature that both eggs, or both embryos, cease to exist and a *third* egg, or embryo, is created. In order to understand Liao's argument we must bear in mind that an egg, or embryo, is an organism. An organism, *as a kind of thing*: a) begins to exist when the capacity to regulate and coordinate the various life processes (respiration, absorption, metabolism, etc.) is there; b) it persists as long as there is a continuing ability to regulate and coordinate the various life processes and c) it ceases to exist

when the capacity to regulate and coordinate the various life processes is permanently gone (Liao 2017). The two main reasons why the enucleation process permanently disrupts the organismic continuity processes of the eggs, or zygotes, are: firstly, that the cytoplasm of an egg, or zygote, contains crucial components for regulating and coordinating the various life processes; secondly, that there are life processes in the cytoplasm of an egg, or zygote, that the nucleus does not control (fully, at least) (Liao 2017). What this means is that an egg's capacity to regulate its metabolism, for example, is destroyed when we enucleate it, and thus *a new capacity* comes into being when we transfer the intending mother's maternal spindle into the donor's enucleated egg. This metaphysical stance is relevant when morally assessing MRTs, as it follows from it that 'in essence' neither technique is therapeutic. They are not therapeutic because they *do not cure anyone*; they just bring into existence a new organism.

By maintaining that numerical identity follows the nuclear DNA, Wrigley et al. appear to endorse the view that cells are essentially their nuclear genes (or a collection of them). But if *genes* are what establish numerical identity then why is the mtDNA not part of what constitutes the numerical identity of a cell, as it also contains genes? Why consider only the nuclear genome and not that plus the mitochondrial one? And equally, why is it the case that *all* the chromosomes establish numerical identity and not only a subset of them? Wrigley et al.'s (2015) view does not offer a compelling case of the notion that cells are essentially their nuclear genomes.

According to the previous arguments neither MST nor PNT are therapeutic and hence a moral case for them and, more importantly, for restricting their use cannot be based on how the welfare of a *particular* child will be improved. These considerations have two implications: on the one hand, it is necessary to abandon the rhetoric of cure and therapy and on the other that additional reasons should be presented to ground the moral case in favour of MRTs. Let us now consider another argument that could justify the moral acceptability of MRTs: reproductive freedom.

### 3.5 Reproductive Freedom and MRTs

Those who have advocated the legalisation of MRTs in the UK have frequently appealed to the importance of allowing couples at risk of transmitting an mtDNA disease the freedom to choose to procreate according to their preferred life plan: what is commonly referred to as reproductive freedom or procreative liberty<sup>134</sup> (Brock 2005; Buchanan et al. 2001; Robertson 1994; Robertson 2003) They argue that couples should be free to choose whether to have genetically related healthy children and that third parties – be them the state, religious institutions or fellow citizens – should not interfere with their choices. For example, Andrew Miller, the chair of the UK's Commons Science and Technology Committee from 2010 to 2015, argued against the lobbying efforts by religious groups to reject MRTs:

It is utterly outrageous in a free society for the churches to tell parents who are in this painfully difficult position that they cannot undergo procedures like this.  
(Mason et al. 2017)

Why was Miller angered by the churches' interference in procreative decisions? In this section, we firstly try to make sense of Miller's (and other defenders of reproductive freedom) outrage, and we then show that if MRTs fall within the remit of the reproductive freedom of heterosexual couples where women are at risk of transmitting an mtDNA disease, then they also fall within the remit of the reproductive freedom of lesbian couples.

In contemporary Western democratic societies, freedom of choice is defended from third parties' interference on political and moral grounds. This has its roots in the work of John Stuart Mill and other liberal philosophers. Mill believed that the only appropriate moral ground for interference in one's actions is if one's free agency may cause harm to others (Buchanan et al. 2001; Mill 1979/1859). In *On Liberty*, he asserts that there should only be "one very simple principle, as entitled to govern absolutely

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<sup>134</sup> Here we do not distinguish between the different expressions used to refer to reproductive freedom (i.e. reproductive autonomy and procreative liberty).



the dealings of society with the individual in the way of compulsion and control". The principle states that:

[T]he only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. (1979/1859)

The former is commonly known as Mill's 'Harm Principle', a principle that sits at the core of our liberal democratic societies, where the presumption in favour of the freedom of citizens to make their own choices without interference places the burden of proof on attempts to limit freedom (Mills 2013).

Isaiah Berlin (1969) labelled this Millian understanding of freedom as *negative freedom* or *freedom from* (Berlin 1969). Elements of this negative understanding of freedom survive in defences of the moral right of people to make "autonomous choices in matters of procreation" (Harris 1998) or, as John Robertson (1994) puts it: "the freedom to reproduce or not to reproduce in the genetic sense" (Robertson 1994). John Harris, John Robertson, Dan Brock and other contemporary advocates of reproductive freedom strongly emphasise the importance of defending the freedom of people to make significant choices in matters of procreation without third parties' interference. They also maintain that this procreative freedom ought to be limited only if it becomes incompatible with a like liberty for all or if it may cause significant harm to others. Harris' and Robertson's theorising of reproductive freedom only in negative terms has been criticised most notably by Catherine Mills, who argues that reproductive freedom also contains positive elements and who understands it as a "practice of self-making", one that allow prospective parents to "give shape" to their lives (Mills 2013). In this sense, reproductive freedom not only incorporates the negative elements of the Millian liberal tradition but also some of the positive elements that Berlin also identified, those that allow for self-determination and that make our actions the product of our own agency (Berlin 1969).

But why does reproductive freedom matter? Why is it a constant reference and point of contention in debates on assisted reproduction? Different authors have provided (slightly) different accounts of why reproductive freedom ought to be treated as a fundamental moral good, but at the core of all these accounts are two

moral bases for its defence: the centrality of reproduction for the development of personal life plans (the autonomy argument for reproductive freedom) and for the well-being of individuals (the welfarist argument for reproductive freedom). The autonomy argument grounding reproductive freedom refers to the morally relevant interest of individuals shaping their own lives according to the values or interests which are relevant to them (Dworkin 1993; Schaefer & Labude 2017). Reproductive freedom is thus important not in itself but due to “the values or interests or standing that this particular constraint defeats” (Dworkin 1993). Applied to the MRTs debate, the argument of autonomy provides a sound moral defence of the right of couples at risk of transmitting an mtDNA disease to their children to reproduce as they want and to have healthy children that are genetically related to them. The welfarist argument, on the other hand, focuses on the relevance of reproductive decisions for individuals’ well-being and understands reproduction as “a core human activity” (Robertson 1994) or “fundamental right” (Liao 2015). Failing to respect reproductive freedom and placing constraints on its exercise may negatively impact individuals’ well-being and their ability to lead a good life (Brock 2005). It is for these reasons that reproductive freedom should not be interfered with for *trivial* reasons and that placing limits on reproductive freedom is morally acceptable only for significant reasons, such as the occurrence of significant harm to others <sup>135</sup>.

When we take into consideration our previous discussion on the ‘therapeutic’ nature of MRTs we realise that Mill’s ‘harm principle’ does not relate to a consideration of the created child. What we are maintaining here is that under a personal account of morality and a counterfactual account of harm – “if your act harms someone, then it makes that person worse off than they would have been had you not done the act” (Boonin 2008) – neither PNT nor MST leave created children worse off than they would otherwise have been. Such children are not made worse off by MRTs because the only other available ‘option’ for them is not to exist <sup>136</sup>.

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<sup>135</sup> For a discussion of the limits of reproductive freedom and of limits other than significant harm to others, see Dan Brock and Allen Buchanan et al., chapter six in particular (Brock 2005; Buchanan et al. 2001)

<sup>136</sup> Two things must be clear: firstly, that the only case where someone could be harmed here is if their life is a wrongful one; secondly, that this is a classic instance of the Non-identity Problem.

Our premise that MRTs do not inflict harm to future children leads to the conclusion that these technologies fall, under a Millian understanding of freedom, within the proper remit of the reproductive freedom of women with mtDNA diseases. Given the moral importance of reproductive freedom for people's capacity to be autonomous and for their well-being, we can further argue that *the current UK legislation* on MRTs benefits women at risk of transmitting an mtDNA disease (and their partners). It benefits them as these techniques represent an additional reproductive option, one that allows them to have healthy genetically related children (if they wish to do so)<sup>137</sup>. Then again, (explicitly) *legislating against* MRTs would violate these women's reproductive freedom by restricting their *significant* range of reproductive options and the possibility of enjoying genetic parenthood. The upshot of considering that the moral case in favour of these technologies is that they add a significant reproductive option to prospective parents is that the ethical focus shifts from mainly taking into account questions of the safety and welfare of future children to considering how these technologies have the potential to *benefit* prospective mothers and couples.

At this point we have reached the crux of the issue: namely, the moral reasons for making MRTs available to women at risk of transmitting an mtDNA disease, *ceteris paribus*, also ground their access to lesbian couples as: a) people have a great interest in reproduction because of how it shapes their lives according to the values and

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Expanding on the Non-identity Problem would require more space than is available here. For a compelling case of why children are not harmed, see David Boonin's work on this issue (Boonin 2008; Boonin 2014)

<sup>137</sup> The idea that more choices lead to greater freedom and well-being has been challenged notably in the work of Gerald Dworkin, Nikolas Rose and Barbara Katz Rothman (Dworkin 1982; Rose 1999; Rothman 1985) They have argued that more options can also have the effect of bringing about more perceived and actual responsibilities. Recently, one of us has further elaborated this view in the context of genome editing and assisted reproduction (Cavaliere 2018a) In the case of MRTs and couples at risk of transmitting an mtDNA disease, however, the range of (reproductive) options currently available includes either refraining from having offspring who are genetically related to both prospective parents or risking passing on the mtDNA disease. MRTs would allow the additional option of having healthy children who are genetically related to both prospective parents. Similarly, as shown above, the (reproductive) options currently available to lesbian couples do not allow them to enjoy genetic kinship. For these reasons, MRTs could be said to count not only as a *mere quantitative* addition to the range of options currently available to prospective parents but as a *qualitatively significant* new option. We are indebted to an anonymous reviewer for bringing this point to our attention.

interests which are relevant to them, and it is also a very deep personal and private project which has a significant impact on individuals' well-being and b) the fact that MRTs cannot be said to harm any child created through their use. Finally, the fact that lesbian couples need a sperm donor, in addition to their own eggs, does not detract from our stance. It does not do so as sperm donation for family-making purposes is morally acceptable (Brandt et al. 2017).

At this point it would be possible to counter that mitochondria *only* produce energy and *only* represent .1% of the total amount of genetic material, and thus that lesbian couples opting for them would just be embarking on a very expensive vanity project. Explaining in detail why these claims, which John Appleby (2017) has named the 'qualitative claim' and the 'quantitative claim', are problematic for arguing that MRTs cannot establish parenthood would require much more space than we have available here (Palacios-González 2017b). What we can state is that, following our previous section on how MRTs affect numerical identity, in the case of a lesbian couple both mothers would be parents under a causal account of parenthood, at least. They would be so because:

[A]ny [free] action that reasonably foreseeably results in the birth of a child generates responsibilities for that child. (Fuscaldo 2006)

And in this case their free action of seeking MRTs, and the subsequent assisted reproductive steps, reasonably foreseeably results in the birth of a child.

### 3.6 Reproductive Freedom and Treating Like Cases Alike

The possible use of MRTs as a reproductive option by lesbian couples has already been mentioned in the bioethics literature by the Nuffield Council on Bioethics (2012), Françoise Baylis (2013), Palacios-González et al. (2014), Rebecca Dimond (2015), Ishii (2014), and Segers et al. (2017). Furthermore, from a legal point of view, Danielle Griffiths (2016) has explored how the UK regulations on MRTs reproduces the hetero-normative genetic family.

However, in such literature, this possible application of MRTs is typically mentioned only in passing. A notable exception is Françoise Baylis. In her article

‘The ethics of creating children with three genetic parents’ she lists this possible use of MRTs under the heading ‘Harms to society’. She asserts:

While the initial goal of mitochondrial replacement technology is ‘therapeutic’ insofar as it aims to avoid the birth of a child with mitochondrial disease, this technology could be used without therapeutic intent. For example, it could be used to pursue non-therapeutic reproductive goals – imagine, a lesbian couple where both partners wanted a genetic link to the children they intend to parent. (Baylis 2013: 533)

Why the use of MRTs by lesbian couples would be harmful to society remains unclear in her article. With some exercise of imagination, and assuming that she in fact believes so, it seems that such harm stems from the fact that this use of MRTs would not be ‘therapeutic’, understanding therapeutic in the sense that “it aims to avoid the birth of a child with mitochondrial disease” (Baylis 2013). Non-therapeutic uses of technologies have been frequently condemned by bioethics scholars because they may corrupt values that we cherish (Sandel 2007); they may damage our relationships among members of a society of equals (Habermas 2003) and they may be instances of eugenics (Sparrow 2011a). However, despite Baylis’ concerns, morality demands treating like cases alike: if we accept that the use of MRTs by women at risk of transmitting an mtDNA disease neither harms society because a child without a mitochondrial disease would be created, nor spare any individual from suffering, then we have to accept that the use of MRTs by lesbian couples does not harm society because a child without a mitochondrial disease would be created, nor spare any individual from suffering. It is true that both types of uses could be considered ‘eugenic’, rather than ‘therapeutic’, in the sense that they aim to bring a particular kind of individual into existence: healthy people who are genetically related to their parents. It is for the above-mentioned reasons that we find Baylis’ position wanting. All the more so, denying access to MRTs to lesbian couples is ethically unjustifiable in as much as it curtails the enjoyment of certain freedoms to a certain group without good reason, whilst allowing others to enjoy the very same freedoms. Those who want to prohibit the use of MRTs by lesbian couples need to

present an argument for showing that them obtaining access to this technology is unethical, an argument that so far no-one has successfully presented <sup>138</sup>.

### 3.7 Genetic Relatedness and MRTs

Let us take stock of what we have argued thus far. We have presented some arguments against the view that MRTs are *therapeutic* technologies and hence concluded that concerns for the welfare of the future child cannot ground their moral acceptability nor restrict their use. We have then focused on the other reason that may morally justify offering MRTs, namely the reproductive freedom of prospective parents. We have argued, *contra* the position of those who want to restrict use of MRTs only to women at risk of transmitting mtDNA diseases, that morality demands treating like cases alike; and we maintain that a concern for equality would deem immoral a restriction on the use of MRTs based on one's belonging to a group with certain sexual preferences. In this final section, we consider a potential objection to our argument: namely that the desire for genetic relatedness is not a morally sufficient reason to allow lesbian couples to access MRTs.

One of the criticisms against MRTs, and against other reproductive technologies, is that their sole benefit is to allow parents to have a genetic tie to their offspring, which is considered a morally dubious end (Rulli 2016a). In this section, we refer to this as the genetic-relatedness objection (GRO) to MRTs. Underlying the GRO are two distinct types of concerns, one inspired by deontological concerns and the other inspired by consequentialist concerns. Deontological concerns (GRO-d) centre on the morally dubious character of those seeking genetic relatedness. This desire is suspect, critics argue, because it expresses a non-virtuous parenting attitude, one

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<sup>138</sup> At this point, someone might claim that the possibility of mito-nuclear incompatibility speaks against the use of MRTs by lesbian couples. We can reply to this challenge in the following way. Firstly, there can be lesbian couples where both women belong to the same haplogroup, and thus even if such interaction-worries materialise for them they would not be a problem. Secondly, at this point in time, as the HFEA report mentions, such putative problems are theoretical, and even if they were to materialise lesbian couples should still have the option of resorting to MRTs (unless the created lives were wrongful ones). This position is not a radical one, but just the same as that that postulates that couples should be able to resort to assisted reproduction even when they know that their children might be at an elevated risk of having a disability.

that aims at having *particular kinds* of children, which is considered by critics ‘a wish and not a need’ (Baylis 2013; Sandel 2007). We do not explore further the GRO-d, as others have done so (Overall 2012). Other concerns underlying the GRO are consequentialist in nature (GRO-c). GRO-c focuses on the negative consequences which allowing prospective parents to use MRTs (and other ARTs) may generate. The negative consequences identified by the critics include: concerns for the resources needed to develop new technologies and how these resources may be employed for other more pressing medical needs (Baylis 2013; Rulli 2016a); the reinforcement of ideas on the importance of genetic kinship for family-making and on the role of genetics more generally to determine our identities (Petropanagos 2017; Rulli 2016a); the medicalisation of a social preference (Petropanagos 2017; Rulli 2016a) and the reinforcement of the two-parent (heterosexual) genetically-based model of the family (i.e. bionormative conception of the family) (Baylis 2017a).

At first sight, the initial type of GRO-c concerns, those hinging on the scarcity of available resources, seems to be legitimate. In practical terms, what this concern means is that, when we argue about the moral permissibility of MRTs, we have to factor in the costs of *satisfying this preference*, even if it is a strongly held one, against other medical opportunity costs, for example *satisfying the basic medical needs of others*. According to Baylis, once faced with this choice we have to reach the conclusion that research and clinical practice on MRTs is immoral. It is immoral given that it uses scarce medical resources that could be better used elsewhere, because, as noted by Rulli and others, the development of MRTs requires(-ed) the use of vast resources both in terms of budget and personnel (Rulli 2016a). One way to respond to this objection is to note that even if we grant Rulli’s and Baylis’ point regarding the use of scarce medical resources, from this fact it *does not inherently follow* that the use of medical scarce resources for MRTs is immoral. This is because in order to make such a claim we need to prove that when compared against all other medical research that is being carried out the use of scarce medical resources for MRTs is unwarranted (Palacios-González 2017c). Our concern here is *not* to examine the ethical case in favour of or against MRTs nor to provide an account of the ethical issues surrounding these techniques, but rather to stress the need to *extend the existing criteria of access to these techniques to lesbian couples*. Furthermore, concerns related to the

necessary clinical research to develop MRTs do not apply in the case of lesbian couples, as these techniques are already in place; and in fact the use of MRTs by lesbian couples, and possibly by other non-mtDNA infertile couples, should be factored in when considering the overall offsetting of the costs of this research.

Lastly, we consider GRO-c concerns related to the reinforcement of genetic deterministic ideas about the importance of genetic relatedness for family-making, and the reinforcement of the bionormative family. Many women and couples have a strong preference for having genetically related children<sup>139</sup> (Hendriks et al. 2017). This former fact is true for both women with mtDNA diseases and lesbian couples, and we contend that in a liberal society allowing only heterosexual couples to enjoy the satisfaction of their wish, regardless of its philosophical validity, is problematic from the point of view of equality. This is akin to only allowing certain ethnic groups to access assisted reproductive technologies, for example.

In addition, gay and lesbian couples' reproductive choices are already limited: depending on the countries' regulations, these couples are often ineligible for third-party reproduction and for adoption. Preventing them from using an already existing technology due to consequentialist concerns related to the reinforcement of genetic determinist ideas on the value of genetic relatedness seems to us akin to further restricting their already limited agency with respect to reproductive options<sup>140</sup>. Hence, even though it is true that we should be attentive to the fact that MRTs could contribute to increasing the value attributed to genetic relatedness, to the detriment of other forms of family-making, it must be said that it would be morally

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<sup>139</sup> One may dispute, as previously stated, that MRTs allow couples at risk of transmitting an mtDNA disease and lesbian couples to achieve the same end, namely to have genetically-related children. While for the first group of couples MRTs allow them to have children whose genetic make-up contains genetic information from both nuclei of the parents, for lesbian couples the situation is different as one party of the couple would provide the nuclear DNA and the other would provide the mitochondrial DNA. The *sociological* question of whether contributing with 'merely' the mtDNA would be sufficient for lesbian couples to regard the children born thanks to the aid of MRTs *as their own* is yet to be answered. However, we maintain that the legislature should not a priori rule against this, based on the idea that mtDNA contributes less to genetic kinship than nuclear DNA.

<sup>140</sup> From *The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015* it is not at all clear if in the UK MRTs can only be accessed by heterosexual couples, or if lesbian couples could access them if one of the intending genetic parents is at risk of passing on a serious form of mtDNA disease.



problematic to just focus on lesbian couples and their wishes and choices thereof. In other words, we believe that it is compatible to hold the view that reproductive technologies such as MRTs might have undesirable consequences such as the ones described by the critics of these technologies, and the view that genetic relatedness seems to be an important good whose enjoyment should not be restricted on an arbitrary basis.

Regarding GRO-c concerns for the preservation of the bionormative family, it must be noted that in the case of MRTs being used by lesbian couples this charge does not apply. The use of MRTs by lesbian couples in fact defies the current dominion of the bionormative family in that it challenges the *folk assumption* about the *correct type and amount* of shared genes that are necessary for establishing a parental genetic link – 50% of the nuclear genes from the father and 50% of the nuclear genes from the mother <sup>141</sup> (Palacios-González 2017b). Specifically, what it is asserted here is that .1% of an mtDNA genetic connection *suffices* for establishing genetic parenthood <sup>142</sup>. Even more so, regulating MRTs so as to include lesbian couples would expand the models of *state-recognised* genetic relatedness and challenge the existing order, and, as seen by Griffiths, not doing so would be:

[A]n example of how science and regulation seek to expand models of traditional relatedness in a way that doesn't challenge the [bionormative] existing order. (Griffiths 2016)

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<sup>141</sup> It must be noted that in the *reproductive cloning debate*, some authors already acknowledge the possibility of becoming a genetic parent through mtDNA. Mary Mahowald, for example, asserted that “through use of one woman’s nuclear DNA and another woman’s enucleated egg, a lesbian couple may have a child who is biologically related to both without requiring sperm donation” and that “the ovum in which that parent’s DNA is inserted represents a significant environmental influence on development, and the mitochondrial DNA adds a genetic component to the environment of the nuclear DNA” (Mahowald 2000). Others who have commented on this issue are Jean Chambers, Timothy Murphy, and Carson Strong (Chambers 2001; Chambers 2002; Murphy 1999; Strong 1998).

<sup>142</sup> It must be noted that this claim aims at subverting the *folk western conception of genetic parenthood*, and that it is not a claim regarding the metaphysics of reproduction. For an account of why MRT-conceived children do have three genetic parents see Monika Piotrowska’s *Is ‘Assisted Reproduction’ Reproduction?* (Piotrowska 2017).

### 3.8 Conclusion

In this paper, we have challenged the view that MRTs are a therapy for mitochondrial diseases, and that these techniques can be considered harmful to children. We have argued that the rationale for offering these techniques must lie somewhere else, namely within concerns for the reproductive freedom of prospective parents. Shifting the focus of the moral debate on MRTs from concerns for the welfare of the children to other moral justifications for offering them allows for the emergence of other issues that require moral consideration. In particular, it allows us to consider how an unduly restrictive approach to accessing MRTs to a particular group requires arguments that have not been presented thus far. We do not want to defend here the wish for genetic kinship as an absolute good that trumps other considerations and nor do we believe that reinforcing a family-making process that includes a genetic element is without costs. However, we remain convinced that these considerations cannot be employed solely to bar access to MRTs by lesbian couples, a group with an already limited range of reproductive options, as this would be immoral from an equality standpoint.

### 3.9 Declaration

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#### 4 Conclusions to Part II: Genetic Relatedness Revisited

Since the advent of IVF, several assisted reproductive technologies have been developed to allow couples, women and men to have children who are genetically related to them. One could go as far as to claim that the whole assisted reproductive technologies industry – from IVF to in-vitro gametes – is not only driven by people's wish to have children but also by the wish to have children who are (healthy and) genetically related to them (Mertes 2014).

The question of what conceptually counts as genetic parenthood is a matter of debate (see, for instance, Douglas & Devolder 2018; Mertes 2014; Piotrowska 2017). What divides authors is whether there could be a conception of this parenthood able to capture the necessary and sufficient conditions for attributing it. Some, such as Heidi Mertes (2014), after assessing different conceptions of genetic parenthood, conclude that:

There is no fixed, scientific, everlasting criterion of genetic parenthood that everyone can agree upon. Quite on the contrary, the concept is increasingly challenged by new and hypothetical interventions in reproductive medicine. (Mertes 2014: 745)

To this rejection of a unitary account of genetic parenthood, Thomas Douglas and Katrien Devolder (2018) have recently responded that even if Mertes (2014) correctly rules out certain conceptions of genetic parenthood<sup>143</sup>, from this it does not follow that no plausible account of genetic parenthood can be obtained. They propose their own conception of genetic parenthood: 'Modified Direct Proportionate Genetic Descent' (Douglas & Devolder 2018). According to this conception:

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<sup>143</sup> Mertes (2014) presents two potential conceptions of genetic parenthood. The first is grounded in the idea of overlapping genetic material between parent and child. According to this conception: "A child is my genetic child when it has 50% of my DNA or when it has 23 of my chromosomes" (Mertes 2014: 744). The second conception is grounded in the idea of direct descent. According to this conception: "X is a genetic child of Y if X is directly derived from Y's genes" (Mertes 2014: 744).

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P is C's genetic parent if and only if (i) some proportion X of C's genes derived from P's genes, and (ii) not through deriving from the genes of some third, intervening individual M from whom C derived proportion Y of his genes.  
(Douglas & Devolder 2018: 10)

Douglas and Devolder's (2018) conception of genetic parenthood seeks to capture folks' understanding of this term and to establish its theoretical core.

Other than the question of whether there can be a unitary account of genetic parenthood despite the variety of possibilities opened up by new technologies, these discussions hinge for instance on whether technological advances such as stem cell-derived gametes will produce embryos with no genetic parents (Mertes & Pennings 2008; Sparrow 2012); whether new technologies such as MRTs will change the way we think about genetic parenthood (Dimond & Stephens 2018a; Griffith 2016); and whether genetic, causal, or other conceptual accounts of parenthood should be adopted (for a discussion on this, see Millum 2017). This debate has practical implications, as new reproductive technologies provide people with new ways to achieve parenthood and as they change the way parenthood is perceived. Notions such as 'social', 'genetic', 'gestational', and 'mitochondrial' parenthood are becoming increasingly disentangled. As Robert Sparrow (2012) puts it, these technologies have "provoked and required a proliferation of concepts of the 'parental' relation" (Sparrow 2012: 174). This conceptual debate is hence linked to the normative debate on genetic parenthood discussed in Paper 3 (Cavaliere 2018a) and Paper 4 (Cavaliere & Palacios-González 2018), as what (conceptually) counts as genetic parenthood has practical implications for debates on the ethics of new reproductive technologies. A central question within these debates is whether the preference to have genetically related children should be satisfied.

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A number of authors from different disciplinary backgrounds have interrogated the ethical standing of the preference for genetically related children (Overall 2012; Rulli 2016b); unpacked the existential and psychological motivations for 'wanting an own child' (Lesnik-Oberstein 2007); the potential societal consequences and the costs of developing technologies to satisfy it (Petropanagos et al. 2015; Roberts 1997); and

surveyed people's reproductive preferences (Hendriks et al. 2017). The normative question of whether people's preference to have genetically related children ought to be satisfied continues to divide authors. The debate on MRTs is a case in point, as the ethical standing of the preference for genetically related children has been at the centre of a controversy within the wider ethical debate on MRTs<sup>144</sup>. Should, then, new reproductive technologies be developed in order to satisfy people's preference for genetically related children?

If we want to answer this question affirmatively, a fruitful strategy (and indeed, one of the most commonly employed strategies to do so) is to establish that people's well-being, sense of identity, and self would be seriously compromised were this preference not satisfied. Other things being equal, it seems uncontroversial to maintain that it is preferable to protect and promote people's well-being, sense of identity, and self rather than significantly compromise them, if doing so does not cause significant harm to others<sup>145</sup>. Establishing a link between satisfying the preference to have genetically related children and well-being, sense of identity, and of self, entails showing that such preference is inherent to what Bernard Williams (1981) refers to as 'ground projects'<sup>146</sup> (Williams 1981, Ch 1) rather than just a contingent or fleeting whim. Establishing such a link entails also that, in turn, *not* satisfying this preference may have negative consequences for people. It is this link between personal well-being, sense of self, and identity on the one hand and the preference for genetically related children on the other that authors such as John A. Robertson (1994, 2003); Harris (1998); Cavaliere & Harris (2018)<sup>147</sup>; Brock (2005);

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<sup>144</sup> See for instance Baylis (2017a) and Rulli (2016a), and Baylis' (2018) response to Paper 4.

<sup>145</sup> Whether satisfying this preference can be or is harmful to others is discussed below.

<sup>146</sup> Williams argues: "For a project to play this ground role, it does not have to be true that if it were frustrated or in any of various ways he lost it, he would have to commit suicide, nor does he have to think that. Other things, or the mere hope of other things, may keep him going. But he may feel in those circumstances that he might as well have died" (Williams 1981: 13).

<sup>147</sup> In this co-authored paper with John Harris, we discuss reproductive freedom and access to abortion within the context of Northern Ireland. Cavaliere & Harris (2018) is not incorporated into this thesis.

Mills (2013), and others who reflect on and defend reproductive freedom seek to establish in order to provide a positive answer to the question outlined above.

If instead we want to provide a negative answer to this question, different strategies can be used. A first set of strategies tries to show that satisfying this preference could be harmful for third parties<sup>148</sup>. Satisfying this preference could, for instance, be harmful for future children as parents may then have “unrealistic expectations” for them (Overall 2012: 63) and as these technologies may not be entirely safe, a discussion that is however complicated by the non-identity problem (Parfit 1984). This is what Baylis (2017a); Inmaculada de Melo-Martín (2017a); and other authors who are sceptical of both the safety of certain reproductive technologies such as MRTs and their value have argued. Alternatively, authors could show that satisfying this preference could be harmful to other members of society. It could be harmful to the very large number of children who are waiting to be adopted (Friedrich 2013; Rulli 2014); it could be harmful due to the opportunity costs of investing in new reproductive technologies instead of in the development of treatments for people affected by medical conditions that do not receive sufficient resources (Baylis 2017a; Rulli 2016a); it could be harmful to members of ethnic minorities who are systematically excluded from enjoying the benefits of assisted reproductive technologies (Roberts 1997, Ch 7); and to disabled people if these technologies are used to have children who are free from genetic or chromosomal conditions affecting the prospective parents (Garland Thompson 2012). What all these assessments have in common is that they try to establish how satisfying the preference to have genetically related children may cause harm (or may risk causing harm) to third parties, which provides at least a *prima facie* ethical reason not to develop technologies to satisfy this preference.

A second set of strategies to offer a negative response to the question of whether new reproductive technologies should be developed to satisfy people’s preference for genetically related children seeks to undermine the importance of this

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<sup>148</sup> I return to this issue in Part IV with respect to the actual and potential harms that can result from protecting reproductive freedom and individual interests in procreative matters.

preference. For instance, Baylis (2017a) argues that such a preference, albeit strongly held, is just part of “acquired desires (i.e. wants)” as opposed to “natural desires (i.e. needs)” (Baylis 2017a: 13). As mentioned in the introduction to Part II, Baylis (2017a) states that while natural needs are always good for us and are often necessary to stay alive, acquired desires (i.e., wants, wishes, and preferences) are neither necessarily good for us nor fundamental to the continuation of our existence. Others argue that this preference is determined by political and cultural contexts and it is the product of pervasive social pressure (Harwood 2007; Petropanagos et al. 2015; Roberts 1997). According to these views, such pressure compels women to use reproductive technologies which can be physically, psychologically, and financially costly (Overall 1993; Petropanagos 2017; Petropanagos et al. 2015), and that influences and distorts people’s preferences. For instance, Angel Petropanagos (2017) argues that:

As pervasive social biases, pronatalism and geneticism can interfere with autonomy by unduly influencing an individual’s reproductive values, preferences, and desires or *by compromising her capacity for critical reflection or action*. [...] These social biases might impose values on individuals that are, in some sense, *not their own* because they might not adopt these values in the absence of pronatalism and geneticism. ([emphasis added] Petropanagos 2017: 133-34)

Re-interpreting the preference to have genetically related children as caused by external influences, socio-cultural and political pressure, and acquired desires is a strategy aimed at questioning the authenticity and the legitimacy of this preference’s ascription to the category of ‘ground projects’.

Providing a detailed analysis and assessment of all the arguments advanced in responses to the question outlined above is beyond the scope of this thesis. What emerges from an analysis of the literature on genetic relatedness and reproductive technologies is once again how different views and responses are the result of competing values and ethical beliefs. These competing values and ethical beliefs concern, for instance, how far technological innovation should go; what weight should be given to people’s preferences; what costs should be tolerated to satisfy

these preferences<sup>149</sup>; whether social preferences should be ‘techno-fixed’; what constitutes tangible and intangible harms; and whether such harms warrant the curtailment of people’s freedom<sup>150</sup>. What I have tried to do in the papers incorporated into this part of the thesis is to add the question of genetic relatedness into the mix of debates on the ethics of genome editing as a reproductive option, and to test whether it can constitute a conclusive argument against expanding criteria of access to MRTs. In the introduction to Part II, I argued that the question of genetic relatedness applies differently to the case of genome editing and MRTs. As I hope became clear after reading the two papers incorporated into this part of the thesis, however, discussing this question within debates on the ethics of genome editing and within debates on the ethics of MRTs brings up different ethical considerations. While in the case of genome editing the question of genetic relatedness concerns the decision of whether to invest resources to develop a new technology that could satisfy this preference, in the case of MRTs these technologies already exist and the decision would be whether to restrict or not give access to this technology to a group of people based on their sexual preferences.

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The work of social scientists belonging to the feminist and/or critical thinking traditions has produced scholarship that can aid a critical discussion of the preference to have genetically related children. This scholarship provides evidence in support of the view that women and couples may suffer from a kind of social pressure that plays a role in the decision to use new reproductive technologies (Harwood 2007; Russo 1976); it has questioned whether these technologies really empower women by allowing them to fulfill their true desires (Petropanagos 2017); it has shown that ‘non-tangible’ harm to third-parties can occur (Roberts 1997); and that competing duties might trump the moral right to reproductive freedom (Rieder 2015b, 2016; Rulli 2016b). These assessments and data are valuable material for debates on the ethics of new reproductive technologies and, even if IVF is routinely used, even if

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<sup>149</sup> This is discussed in Papers 3 and 4, and Part IV of this thesis.

<sup>150</sup> I discuss this question in Part IV.



MRTs have been legalised in the U.K., it does not follow that ‘anything goes’ with respect to the development of ever newer technologies.

It is true that people’s value systems can change, that preferences can be readjusted, that one can have all sorts of wishes and wants and not all of them should be satisfied. Despite this, at present, for some, *not* having (genetically related) children can be experienced as a dramatic event and it could have a significant impact on their well-being. This might and perhaps should change, but charges of false consciousness and of having misguided preferences, and attempts to debunk such preferences do nothing to help the people who are suffering from infertility or genetic conditions. In addition, changing people’s preferences should not come at a significant cost to those who strongly hold such preferences. This is what I find problematic in the accounts of those who take as a point of departure for their critiques of new reproductive technologies the lack of authenticity and significance of people’s reproductive preferences. Whether something is ‘acquired’ or ‘natural’, the product of cultural and political contexts or of biology seems less relevant than whether something positively or negatively affects people’s well-being and sense of self. Reproductive preferences and wishes can be questioned and acquiring data concerning their biological, cultural, and political driving forces and origins will likely provide important insights to the debate on their ethical standing. But these endeavours should go hand in hand with a commitment to respect and promote when possible people’s well-being and sense of identity. If this is best achieved by lightening the negative effects of the social pressure mentioned above (especially on women); by reducing actual and potential harms to discriminated and vulnerable groups<sup>151</sup>; by countering certain stereotypical ideas of what counts as the *optimum* in parenting; by satisfying preferences with technical or non-technical means, seems to be ethically irrelevant.

Does this translate into an imperative to continue to invest our limited resources into the development of ever newer technologies? Or that basic research to develop new technologies and clinical applications of these technologies should always go

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<sup>151</sup> I return to this issue in Part IV of this thesis.

forward? In my view, it does not. What ultimately matters is to balance the burdens and benefits of different courses of action, and to proceed justly in their distribution. The question of genetic relatedness, its origins, and ethical standing should feature in these calculations, but only as one of the elements to weigh up and consider in these assessments. In order to do so, it is necessary to move from an analysis of debates on the ethics of new reproductive technologies (Part I) and from a discussion of the ethical standing of eugenic decisions and of the preference for genetic relatedness just discussed, to another set of relevant ethical questions. To understand how competing interests are dealt with in practice, it is necessary to focus on questions concerning the governance of new reproductive technologies (Part III) and to address ethical questions pertaining to the effects of procreative decisions more generally (Part IV). I discuss questions of governance and of the costs of satisfying people's procreative preferences in these remaining parts of this thesis.

# PART III

## Regulating New Reproductive Technologies

### 1 Introduction to Part III

In this part of the thesis, I move from questions pertaining to the ethics of new reproductive technologies to questions pertaining to how new reproductive technologies should be regulated within democratic societies and who should decide how to regulate them. In Paper 6 (Cavaliere et al. 2019), the final paper incorporated into this thesis, my co-authors and I refer to questions concerning the governance of new reproductive technologies as ‘ethical-political’ questions arising at the ‘second level’ of ethical analysis. We distinguish them from ethical questions arising at the ‘first level’, which pertain to the ethical standing of a given technology and of its applications<sup>152</sup>. In Paper 5 (Cavaliere 2017) and Paper 6 (Cavaliere et al. 2019), the two papers incorporated into Part III, I discuss second level ethical questions raised by two developments in the field of embryology and genetic engineering. This part of the thesis moves to what I argue is another necessary step to providing a thorough assessment of the ethics of new reproductive technologies and to addressing the question of who should come into existence. To recap: Part I of this thesis approached the assessment of the ethics of these technologies by analysing and reflecting on the normative debates which surround them. Part II built on this analysis and concerned more specifically ethical questions and challenges raised by new reproductive technologies. Part III, and the papers incorporated into it, brings together several of the key themes of this thesis including how to address the moral disagreement arising in democratic societies concerning new reproductive technologies; how to negotiate between competing values on the ethical standing of these technologies and their applications, and how to deal with competing world-views on the question of who should come into existence. Contrary to the rest of

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<sup>152</sup> An example of these ‘first level’ questions was given in Part II with respect to MRTs and genome editing technologies.

this thesis, here the focus is on how to act in the public sphere in relation to these themes and how to address these questions in the realm of public policy. I contend that this evaluation and assessment of ethical-political questions surrounding new reproductive technologies is necessary to produce a thorough assessment of the ethics of new reproductive technologies and to address the question of who should come into existence from all its relevant dimensions.

Paper 5, the first paper incorporated into this part of the thesis, is a single-author paper published in *BMC Medical Ethics* titled ‘A 14-Day Limit for Bioethics: The Debate over Human Embryo Research’. There, I discuss whether the 14-day statutory limit for human embryo research should be extended<sup>153</sup> and defend an approach to addressing this question that aims to find a compromise between competing values and ethical views. Paper 6, the second paper incorporated into this part of the thesis, is published in the *Cambridge Quarterly of Healthcare Ethics* and titled ‘Regulating Genome Editing: For an Enlightened Democratic Governance’. It is co-authored with Dr Katrien Devolder (KD) and Dr Alberto Giubilini (AG). There, I discuss different regulatory approaches to the governance of genome editing applications to early human embryos. I argue for an approach that my co-authors and I dub the ‘enlightened democracy approach’, which is modelled on the framework of deliberative democracy and on Philip Kitcher’s (2001, 2011) idea of ‘well-ordered science’. Both of these papers hence propose and defend strategies to address ethical-political questions pertaining to the governance of two technologies which cause substantial ethical controversy: embryo research and genome editing. The defences of compromise and of the enlightened democracy approach I advance need to be interpreted in terms of attempts to consider and respect the plurality of people’s ethical views and values in relation to these technologies. These defences are motivated, in other words, by a commitment to democratic governance in areas of profound ethical controversy.

Human embryo research and genome editing technologies represent an interesting case study to reflect on ethical-political questions. These technologies have been in

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<sup>153</sup> On this question, see also Sarah Chan (2017, 2018), and Appleby and Bredenoord (2018).

existence for decades, but during the three years of my doctoral research (2015-2018) technical potential significantly improved in both respects. Human embryos can be now sustained in vitro for longer than ever (Deglincerti et al. 2016; Shahbazi et al. 2016); also, genome editing technologies are significantly more precise, efficient, and less costly (Brokowski & Adli 2019; Ledford 2015). These developments raise old and new ethical questions, many of which have been discussed in this thesis. These developments also offer an opportunity to rethink existing and new regulatory approaches, and to reflect on ways to deal with the plurality of views coexisting in democratic societies. I take advantage of this opportunity in the two papers incorporated into this part of the thesis.

My overarching aim in Part III is to show that ethical-political questions deserve ethical attention given the plurality of values and world-views which bioethicists, scientists, other scholars, and citizens hold; how these values and world-views give rise to deep moral disagreement; and the practical implications of such disagreement. Following Hendrik Wagenaar and Sietske Altink (2012), and Wagenaar (2011):

Politics is thus society's ways of dealing with the deep pluralism, the inevitable conflicts of beliefs, religion, value, and interest that characterize all societies.  
(Wagenaar 2011, Ch 10) (Wagenaar & Altink 2012: 280)

It is within these inevitable conflicts that new reproductive technologies need to be discussed and regulated. It is also within them that my analysis is situated.

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Moral disagreement and how to deal with it in the public policy arena is something that has been the locus of concern for political theorists and philosophers alike. *On Liberty*, John Stuart Mill's (1979/1859) seminal work on political freedom and free speech, as well as John Rawls' (1993) idea of reasonable pluralism within the framework of political liberalism can be seen as part of a tradition that attempts to settle this question. In this part of the thesis, I address ethical-political questions raised by new reproductive technologies by borrowing from and building on some of the arguments advanced within a more recent set of approaches devised to deal with moral disagreement within the public policy arena. This set of approaches can be collectively identified as the framework of deliberative democracy (Bohman

1998; Cohen 2003; Dryzek 2000; Elster 1998; Gutmann & Thompson 1996, 2009; Hajer & Wagenaar 2003) which attempts to set out strategies of governance considering the existence and, importantly, the persistence of moral disagreement.

As its label suggests, ‘deliberative democracy’ rests on two tenets: democracy and deliberation. Deliberative democracy’s democratic component is achieved through involving in decision-making processes those who are directly and indirectly affected by the matter in question (Elster 1998). By contrast, its deliberative component is achieved through the mutual exchange of reasons and arguments among those involved in these processes (Gutmann & Thompson 1996; Elster 1998). Capturing these features, James Bohman (1998) defines deliberative democracy as:

[A]ny one of a family of views according to which the public deliberation of free and equal citizens is the core of legitimate political decision making and self-government. (Bohman 1998: 401)

A core characteristic of this family of views (as opposed to other approaches to democratic governance) is that the preferences of those engaged in deliberative processes are not merely aggregated through a vote or a poll but rather transformed and refined through mutual exchanges (Elster 1998). Those participating in these exchanges should be committed to mutual respect and to seeking “fair terms of cooperation” (Gutmann & Thompson 2009: 3). They should also rely on “reason-giving” (Gutmann & Thompson 2009: 3) and on “persuasion rather than coercion, manipulation, or deception” (Dryzek 2000: 1). According to proponents of deliberative democracy<sup>154</sup>, one of the strengths of this family of views is that decisions reached following this mutual exchange are more legitimate in that they receive “reflective assent through participation in authentic deliberation by all those subject to the decision in question” (Dryzek 2001: 651). In addition to legitimacy, another strength of deliberative approaches to democratic decision-making is that decisions may be less subject to epistemic error:

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<sup>154</sup> For an overview and a discussion of critiques of the deliberative democratic approach, see for example Michael Parker (2007); Lynn M. Sanders (1997); Ian Shapiro (1999); Susan Stokes (1999).

### Part III Regulating New Reproductive Technologies

Through the give-and-take of argument, participants can learn from each other, come to recognize their individual and collective misapprehensions, and develop new views and policies that can more successfully withstand critical scrutiny. (Gutmann & Thompson 2009: 40)

Relatedly, these approaches and the ‘give-and-take of argument’ they entail can give rise to new ideas which may not emerge in private deliberation (Fearon 1998) – a view that echoes Mill’s (1979/1859) defence of the freedom of ‘thought and expression’ (Mill 1979/1859, Ch 2; see also Kitcher 2007). Other than instrumental reasons in favour of deliberative democracy, its proponents advance intrinsic or, following Michael Parker (2007), ‘expressive’ reasons in favour of these approaches. The value of these approaches would lie in their embodiment of:

[A] recognition of respect for persons, that is, people should be treated not simply as the object of legislation but as autonomous, if socially embedded, agents capable of taking part in the governance of the societies within which they live. (Parker 2007: 186)

According to this view, then, considering the preferences of citizens, involving them in decision-making processes, and ensuring that their views are heard by fellow citizens and policy-makers *expresses* respect for them.

Within bioethics scholarship, authors have built on this family of views and developed proposals for bioethics to learn from and rely upon certain core elements of deliberative democracy (for an overview, see for example Gutmann & Thompson 1997). For instance, Parker (2007) outlines five techniques for the development of “a substantive and pluralist model of deliberative bioethics” (Parker 2007: 189), which should be:

[G]rounded in and constrained by: respect for persons, reflectivity, focusing on listening to and capturing marginalized voices; modes of expression and overlooked narratives; resisting the erasure of difference; the importance of ‘thick description’; and adopting a critical perspective. (Parker 2007: 189-190)

Other examples of how bioethics scholarship and debates can learn from democracy approaches concern, for instance, the use of PGD for sex selection (Farrelly 2009); genetic enhancement in sport (Camporesi & Maugeri 2011); and research ethics

(Kim et al. 2009). These authors' proposals, and more generally the juxtaposition of deliberative democracy with matters of concern for bioethics have as a peculiar characteristic a shift in the subject matter of what it is to be governed. By and large, deliberative democracy concerns the governance of citizens in democratic societies, while deliberative democracy within bioethics focuses on, building on Rose (2007), the governance of 'life itself'. This shift is especially evident in the analyses of authors who interpret 'public bioethics bodies' (see for instance Kelly 2003) as forms of (enacted) deliberative democracy. These bodies are "institutions, practices, and discourses" (Moore 2010: 715) linking policy-making and ethical considerations to improve political decision-making within the governance of life. Some of these authors charge public bioethics bodies with embodying 'technocratic authority' (Evans 2006); reproducing problematic models of 'expert domination' (Moore 2010); and with creating and reinforcing mechanisms of inclusions and exclusions within deliberations on ethical matters (Hurlbut 2017; Kelly 2003); among other critiques.

In this part of the thesis, I do not attempt to settle the questions this tradition has raised and addressed. In this sense, my analysis is limited in scope and depth. What I focus on is a much more modest project. I examine and address some of the ethical-political questions raised by two recent developments in the fields of genetics and embryology: the capacity to sustain human embryos in vitro for longer than was hitherto technically feasible and is legally possible<sup>155</sup> and the application of genome editing technologies to human embryos. I then propose two approaches to address such questions: favouring a solution of compromise between conflicting ethical views (in Paper 5, Cavaliere 2017) and adopting an enlightened democracy approach (in Paper 6, Cavaliere et al. 2019). These approaches build respectively on strategies devised by Mary Warnock, the chair of the committee established in the U.K. in 1982 to discuss embryo research and assisted conception; and by the framework of deliberative democracy and Kitcher's (2001, 2007) idea of 'well-ordered science'. Together, they represent attempts to address ethical-political questions arising

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<sup>155</sup> As further discussed in Paper 5 (Cavaliere 2017), the current statutory limit for conducting research on human embryos in the U.K. is set at 14 days after fertilisation. The '14-day limit' or '14-day rule' is enshrined in the legislations of 12 countries and embedded in the guidelines of five more (see Hyun et al. 2016; Isasi & Knoppers 2006).



within pluralistic societies. Individually, they represent attempts to address questions pertaining to the governance of embryo research and genome editing applications to early human embryos.

### **1.1 New Developments and Their Relevance for Assisted Reproduction**

As I argued in the introduction to this thesis, I consider genome editing technologies and research involving early human embryos as both eugenic and reproductive technologies. I do so as, albeit not strictly reproductive, these technologies are instrumental to people's reproductive projects and they raise questions pertaining to who should come into existence. People who are at risk of transmitting a genetic condition to their offspring may decide not to reproduce without the aid of these technologies. At the same time, these technologies could satisfy people's preference to have children who are healthier than they would otherwise have been (were these technologies not employed) and genetically related to them (see also: Nuffield Council on Bioethics 2018). One of the arguments used to ground a positive case for basic research with genome editing is that such research – albeit not directly providing a cure for infertility – could shed light on disorders responsible for early miscarriage as well as on genes involved in the early development (and interruptions to the development) of human embryos (Human Fertilisation and Embryology Authority 2016: 1.18). Basic research with genome editing has been also explicitly defended on the grounds that, among other benefits, it could be promising for future infertility treatments.

The focus on potential and future 'reproductive' benefits of research with genome editing was one of the reasons advanced by the research group led by Kathy Niakan at the Francis Crick Institute (based in London, U.K.) in its application to the HFEA. With this application, the Crick group sought permission to conduct basic research with CRISPR on human embryos. In the HFEA Licence Committee minutes, the committee declared itself "satisfied that the activities to be licensed are necessary or desirable" as these activities may provide "increasing knowledge about the development of embryos" and as they may be able to promote "advances in the

treatment of infertility” (Human Fertilisation and Embryology Authority 2016: 1.18). More specifically, the committee declared itself to be:

[S]atisfied that the genes or proteins the team will be studying may, in the long term, be important in understanding human embryo development and in developing biomarkers of embryonic health which might be used in clinical IVF treatment. (Human Fertilisation and Embryology Authority 2016, 1.18)

In other words, the licensing committee recognised how basic research with genome editing on human embryos can be instrumental to people’s procreative projects and explicitly endorsed this research for this reason (see for instance Human Fertilisation and Embryology Authority 2016).

As with today’s discourses on research with genome editing technologies, in the early days of the debate on human embryo research discourses on whether this practice should have been allowed were inextricably tied to assisted reproduction (Wilson 2014). Justifications for legalising these two practices were interwoven for two reasons. On the one hand, the debate on the ethical acceptability of embryo research emerged due to the need to decide the fate of supernumerary embryos created with IVF. On the other, Warnock and others defended this practice on the grounds that it was needed to make IVF and other assisted reproductive technologies safer and more effective (Wilson 2014). Recent developments in embryology and the technical capacity to sustain human embryos in vitro for longer than was hitherto possible marked what can be interpreted as a ‘second wave’ of the debate on human embryo research. Within this debate, the relationship between embryo research and reproduction is stronger than ever. One of the most commonly employed arguments in favour of extending the statutory time limit to conduct human embryo research is that it can shed light on embryo development and on the interruptions to such development responsible for early miscarriage. For instance, Magdalena Zernicka-Goetz, one of the key scientists behind the recent developments in embryology discussed in Paper 5, clarifies:

Why might society want to follow these events? Largely because these are the developmental stages at which many defects in early human development occur. The failure to establish a pregnancy or its termination through natural

### Part III Regulating New Reproductive Technologies

miscarriage resulting in the spontaneous death and loss of a baby is a misery for many would-be mothers. [...] Understanding early post-implantation development will enable us to predict when developmental defects are likely to arise and, with time, to establish treatments. (Zernicka-Goetz 2017 :53)

The idea of allowing human embryo research and of extending the limit to conduct such research in order to cure infertility is indeed one of the most powerful arguments advanced in favour of such research. The strength of this argument becomes evident when contextualised within the relevance of reproductive freedom and of the preference to have genetically related children discussed in the previous part of this thesis. As Charlotte Elves and Sheelagh McGuinness (2017) argue: “Embryos exist in a liminal position between reproduction and research” (Elves & McGuinness 2017: 26) <sup>156</sup>. It is within such a liminal position that my discussion of human embryo research and genome editing technologies is situated.

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Other than being broadly understood in terms of new reproductive technologies, the developments<sup>157</sup> discussed in the two papers incorporated into this part of the thesis are linked in several additional ways. Firstly, as is the case for other technologies discussed in this thesis, they have been depicted as eugenic and substantial moral disagreement surrounds their ethical standing (first level questions) and how they should be regulated considering such disagreement (second level questions). Secondly, many of the arguments presented in favour of and against them are similar as they appeal to (future) benefits, reproductive freedom, the moral status of the embryo, eugenics and ‘slippery-slope’ concerns. Thirdly, the timing of the announcements of the results of the experiments showing that embryos could be sustained in vitro for 12-13 days (Deglincerti et al. 2016; Shahbazi et al. 2016) and of the Francis Crick Institute application to the HFEA is of critical significance, as it provided those in favour of extending the statutory limit for embryo research and

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<sup>156</sup> See also Marie Fox and Sheelagh McGuinness (2015).

<sup>157</sup> As mentioned above, these developments are: the capacity to sustain embryos in vitro for more than 14 days after fertilisation (discussed in Paper 5) and the application of genome editing technologies to human embryos (discussed in Paper 6).

of applying genome editing to human embryos with additional reasons to advocate for a green light on both (see Connor 2016).

Before moving to Paper 5 (Cavaliere 2017) and Paper 6 (Cavaliere et al. 2019), I discuss some of the instrumental and intrinsic reasons in favour of considering views that differ from one's own when we move from ethical questions at the first level to ethical questions at the second level. The literature on deliberative democracy engenders some of these arguments (which are further assessed in the two papers incorporated into this part of the thesis), such as those pertaining to the need to ensure the 'generation of trust' (Hajer & Wagenaar 2003: 12; O'Neill 2002) and to legitimacy (Buchanan 2002b; Cohen 2003; Gutmann & Thompson 2009; Parkinson 2003).

## 1.2 Taking Conflicting Ethical Views into Account

My own theoretical-ethical view of the old question of whether embryo research should be allowed and of the new question of whether the 14-day limit for embryo research should be extended is that there are good reasons to allow embryo research given the benefits that it could yield. I also think that there are good reasons to extend the limit – if extending the limit will lead to substantial scientific gains which could not be achieved were the limit kept at 14 days<sup>158</sup>. I hold this view because I do not think that embryos at 14, 28, 35 days or so have significant moral status and that they should be protected by sparing them from being used for research. It seems to me that they have no interests, no preferences, and no ability to experience pain or pleasure. They lack, in short, all the characteristics necessary (if not sufficient) to be granted moral status and to be spared from being used in research. Similarly, in

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<sup>158</sup> In a recently published article, Appleby and Bredenoord (2018) outlined scientific reasons (benefits for research on synthetic embryos, organoids, genome editing and stem cell-derived gametes); regulatory reasons (in their words: "A failure to revise the 14-day rule places the international community at risk of losing one of its better examples of international consensus and regulation, because the rule itself could be viewed as no longer fit for purpose", Appleby & Bredenoord 2018: 4); and ethical reasons (benefitting "science and patients" Appleby & Bredenoord 2018: 4, and as they could not find valid ethical reasons against extending the rule to 28 days). This article was published after Paper 5 (Cavaliere 2017), but I address within it many of the broader issues these authors raise.

my view, if genome editing could be proven to be safe and effective, there are good reasons to allow basic and clinical research to go forward. These good reasons pertain to the medical benefits of genome editing: it could correct mutations which may lead to harmful genetic conditions. This in turn would allow people that are healthier than they would otherwise have been – had genome editing not be used – to come into existence. I hold this view because, in addition to my position on the moral status (or lack thereof) of human embryos, I do not think that their genetic makeup should be granted special protection.

There may be good countervailing reasons to those I have discussed above, but my view is that these reasons are not provided by an appeal to embryos' full or substantive moral status. Such countervailing reasons could, for instance, be that our (past) experience with embryo research allows us to predict that extending the limit to conduct embryo research is not likely to yield significant benefits in terms of both increased scientific knowledge and increased possibilities for clinical applications of such knowledge. This would be a (good, *prima facie*) reason against embryo research and against extending the 14-day limit notwithstanding one's position on the moral status of the embryos. Similarly, if genome editing was not safe or effective, if allowing people that are healthier than they would otherwise have been to come into existence could be pursued via existing technologies (such as PGD combined with whole genome sequencing), then these would be (good, *prima facie*) countervailing reasons not to allow basic and clinical research with genome editing. These are my ethical views on embryo research, extending the limit to conduct such research and genome editing technologies applications to early human embryos. While I am convinced of the rightness of these ethical views, regulations should not be necessarily based on (or based solely on) these (right) ethical views<sup>159</sup>. When we

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<sup>159</sup> In *Truth or Consequences*, Brock (1987) argues that: "Truth is the central virtue of scholarly work" and that philosophers and scholars more generally are "taught to follow arguments and evidence where they lead without regard for the social consequences of doing so" (Brock 1987: 786). Despite this commitment to seeking truths regardless of consequences, philosophers who lend themselves to public policy would be ineffective and may end up failing in their responsibilities if they continue this truth-seeking business as usual. This, according to Brock (1987), is due to a sort of necessary division of labour between policy-making and academia. Contrary to academia, within policy-making "The first concern of those responsible for public policy is, and ought to be, the consequences of their actions for public policy and the persons that those policies affect" (Brock 1987: 788). In a similar

move from theoretical-ethical debates on new reproductive technologies to debates on how to regulate these technologies, from theoretical-ethical questions at the first level to political-ethical questions at the second level, other considerations come into play and additional reasons (in favour of and against) these technologies need to be carefully considered, both for practical (instrumental) and intrinsic reasons. I discuss some of the instrumental reasons to consider ethical views which differ from one's own and especially from what one considers the right ethical view in both the papers incorporated into this part of the thesis. By and large, formulating policies that do not reflect nor consider in any way ethical views held by a large swathe of the population could engender undesirable outcomes. People may end up becoming increasingly distrustful of both scientists developing technologies, and policy-makers and committees appointed to regulate them (Calnan & Rowe 2008; O'Neill 2002; Resnik 2011)<sup>160</sup>. They could perceive basic and clinical research as businesses which are pursued without constraints and without the (ethical) input of potential users, riding roughshod over users' and society's values and views. They could become increasingly alienated from scientific research and from the products of such research (e.g. from the new reproductive technologies I discuss throughout this thesis).

There may be additional instrumental reasons to consider ethical views which differ from one's own, which can be extrapolated – with some necessary caveats – from Mill's defence of the 'liberty of thought and expression' (Mill 1979/1859, Ch 2). Mill advances four arguments in favour of such liberty: the first two pertain to human fallibility. According to him, suppressed human opinions can be true or they can at least contain some portion of truth. Allowing the inclusion and subsequent

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fashion, Jonathan Montgomery's (2013) reflections on doing 'public ethics' as opposed to academic/scholarly work lead him to conclude that the latter rather than the former "aspires more to acceptability rather than to philosophical neatness" and that "members of committees can adopt conclusions for a variety of reasons, which may be mutually inconsistent, provided they give a basis from which policy can be developed" (Montgomery 2013: 12).

<sup>160</sup> As Maarten A. Hajer and Hendrik Wagenaar (2003) argue, within the 'network society' (Beck 1999) "*Trust cannot be assumed*. Politics and policymaking thus is not simply about finding *solutions* for pressing problems, it is as much about *finding formats that generate trust* among mutually interdependent actors" ([emphasis in original] Hajer & Wagenaar 2003: 12). See also Jack Barbalet (2009) for the performative role of trust in situations of uncertainty and Camporesi et al. (2017) for a discussion of recent work on trust in healthcare.

discussion of rival points of view can guard against epistemic errors. The third and fourth arguments pertain instead to dogmatism and prejudice. According to Mill, received opinion incurs the risk of becoming dogmatically held “in the manner of a prejudice, with little comprehension or feeling of its rational grounds” (Mill 1979/1859: 60) and of losing its meaning thereby becoming “deprived of its vital effect on the character and conduct” (Mill 1979/1859: 60). Once again, allowing the inclusion and discussion of rival points of view can prevent such deleterious developments. Following Mill, then, an instrumental reason to take into account ethical views which differ from one’s own is that ethical views can be liable to error if they are based on empirically and normatively wrong assumptions and premises (or just on partially wrong assumptions and premises). Additionally, moral theories which inform these ethical views may be held dogmatically. The process of engaging with ethical views which differ from one’s own may uncover such dogmatism and compel the questioning of one’s own ethical views and the principles underpinning them before others. This would mean engaging in a process of rediscovering ethical views’ potential to redirect ‘character and conduct’. All these considerations point to instrumental reasons to take into account ethical views which differ from one’s own. Notwithstanding one’s own ethical view on the permissibility of conducting research on human embryos (within and beyond the 14-day limit) and on the permissibility of editing the genetic makeup of early embryos, the different views held by other authors and citizens on both technologies become relevant for the debate on how to regulate them.

This commitment to reflect on ethical-political questions in ways which do not strive to find the ‘right’ ethical way forward was also the approach that Warnock endorsed in her role as chair of the committee appointed to deliberate and advise over the permissibility of human embryo research. In Warnock’s words:

An absolutely central consideration in the work of [the] committee... was the difference between what one might personally think was sensible, or even morally right, and *what was most likely to be acceptable as a matter of public policy...* Time and again we found ourselves distinguishing not between what would be right or wrong, but between what would be acceptable or unacceptable. (Warnock 2003: 98-99, quoted in Franklin & Roberts 2006: 5)

Warnock explicitly rejected “the language of right and wrong” (Warnock 2003: 99) and focused rather on finding something that was ‘acceptable’. Her methodological and normative stance was criticised by philosophers such as Harris (1985, Ch 6), Michael Lockwood (1985) and Hare (1987) for lacking philosophical rigour; failing to provide defensible reasons in support of its recommendations; not discussing fundamental questions concerning the moral status of the embryo and taking into account feelings not grounded in moral principles and reason. While this criticism was an accurate representation of Warnock’s approach, it was misguided as Warnock’s aim was never philosophical rigour and to decide on the right ethical view for the regulation of embryo research but rather to:

[R]ecommend a policy that might allow the sort of medical and scientific progress which was in the public interest, while at the same time not riding roughshod over the moral scruples of a significant number of the public.  
(Warnock 2003, quoted in Montgomery 2013: 11)

Warnock’s approach and the idea of considering a plurality of different ethical views in developing policies to regulate new reproductive technologies can be also defended for intrinsic reasons, i.e. these views would be taken into account for their own sake rather than for the state of affairs they may bring about. Moral pluralism (or value pluralism), namely the idea that there is an “irreducible plurality of values or principles that are relevant to moral judgment” (Wolf 1992: 785), offers both an explanation for moral disagreement as well as grounding a normative commitment to take into account and respect different ethical views on new reproductive technologies<sup>161</sup>.

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<sup>161</sup> Other defences and discussions of moral pluralism can be found in, for instance: Isaiah Berlin (1969); Bernard Williams (1981); Nagel (1979); William D. Ross (1930). Nagel (1979), for example, rejects the possibility of resolving conflicts of values by measuring and outweighing these values against one unitary and foundational value, and the possibility of explaining such conflicts in terms of one unitary value. This is what utilitarianism seeks to do with utility on the one hand by trying to resolve conflicts by prioritising utility over other values and on the other by trying to explain the apparent priority of other values in terms of utility. Nagel (1979) rejects both these moves: “My reasons for thinking that such explanations are unsuccessful, or at best partially successful, is not just that they imply specific moral conclusions that I find intuitively unacceptable (...). Rather, my reason for doubt is theoretical: I do not believe that the source of value is unitary – displaying apparent multiplicity only in its application to the world” (Nagel 1979: 132).



Susan Wolf (1992) begins her essay on moral pluralism with a discussion of the persistence of moral disagreement. She also expresses dissatisfaction with the strategies that are commonly employed to explain away such disagreement, which try to establish that at least one of the parties (or both parties) are subjected to some kind of cognitive (or moral) error. By contrast, Wolf (1992) sets out to explain how moral pluralism “suggests a more tolerant though still antisubjectivist response to moral disagreement” (Wolf 1992: 787). According to Wolf:

In understanding and interpreting moral disagreements, pluralism offers an alternative to the relativist position that my views are right for me and your views are right for you, as well to the absolutist position that only one of us can be right. For the pluralist can understand moral disagreements, at least potentially as cases in which the plurality of values don't add up to a uniquely right answer. (Wolf 1992: 788)

Within a moral pluralist framework, then, the persistence of moral disagreement can be traced back to the irreducible plurality of morally significant values and to the lack of a unifying principle that can both order and explain them entirely<sup>162</sup>.

Conflicts over the moral status of the embryo and especially over the permissibility of human embryo research, extending the 14-day limit and applying genome editing technologies to early human embryos can be explained by the sort of ‘first-level moral pluralism’ described by Wolf (1992). According to this view, those who believe that embryos should be protected and germlines preserved are not necessarily subject to some kind of cognitive error (although they may be), but they are committed to values which differ from those holding another view on the

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<sup>162</sup> According to Wolf (1992), value pluralism differs in relevant ways from subjectivism and from relativism. Contrary to subjectivism, a commitment to value pluralism does not meta-ethically nor normatively entail the view that as far as morality is concerned ‘anything goes’. This view is echoed by Nagel (1979), who warns against the danger of embracing pluralism and noncomprehensive systematisation as a way to abandon *any* attempt to provide moral justifications and to formulate moral theories. Contrary to relativism, value pluralism does not either necessarily entail the relativist position that the truth of an ethical view is relative to the moral standard of some person, society or culture. In Wolf’s (1992) words: “Unlike the relativist, who believes that what is right for you is different from what is right for me, the pluralist holds that, for each and every one of us, the question of what is right in some cases lacks a unique and determinate answer. Rightness, on this view, is not relative to anything, it is not a matter of perspective. It is just indeterminate” (Wolf 1992: 189).

permissibility of these technologies (including my own). This does not translate into the view that *any* ethical view on embryo research and genome editing should be necessarily be held, as irreducibility does not need to translate into the impossibility of rational choice between conflicting justifications and views (Nagel 1979, Ch 9). In addition, while conflicting justifications and views can be reasonable, not all justifications and views are necessarily equally reasonable<sup>163</sup>. Moving from considering conflicting views (or views that differ from one's own) as the result of cognitive errors or morally reprehensible attitudes towards considering at least some of them the result of an irreducible plurality of values provides an intrinsic reason to consider and respect these views.

The question of whether rational choice between conflicting values is possible is a common challenge to the value pluralism framework. In the papers incorporated into this part of the thesis, I do not attempt to settle this question – which has been addressed in terms of following Aristoteles' idea of practical wisdom (Nagel 1979), of attempting to rank conflicting values and prioritise some over others (Griffin 1986; Stocker 1990) and of accepting that certain conflicts cannot be rationally resolved (see, for instance: Berlin 1969; Williams 1981). Instead, in these two papers, on the one hand I aim to provide arguments for considering and respecting the plurality of ethical views on new reproductive technologies in the context of debates on how to regulate these technologies; on the other, I propose two strategies that, in my view, can work towards this aim.

In my view (and as I further argue in Paper 5, Cavaliere 2017, and in the conclusion to this part of the thesis), a solution of compromise between the plurality of values

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<sup>163</sup> To give an example, please allow me to move from moral to aesthetic judgements (and back): an aesthetic pluralist answer to the question of who is the best film director would be that there are several candidates for such recognition. It would also be that there are several possible and plausible justifications for proposing different candidates, but that it may be hard to find non-question-begging justifications for one candidate or another. This does not mean that *any* director can be considered the best (think about deciding between Martin Scorsese and Christopher Nolan on the one hand, and between Quentin Tarantino and Tommy Wiseau on the other) nor that it is impossible to reject certain candidates or justifications. Similarly, a moral pluralist answer to the question of whether embryo research should be permitted would allow for contrasting ethical views and justifications to be considered as reasonable answers to such a question, but not to *any* answer (think about the difference between a view that defends such permissibility if there are no benefits yielding from such research and if embryos are proven to be experiencing pain).

and conflicting ethical views concerning new reproductive technologies is a strategy that considers and respects these values and views. Despite this, defending a solution of compromise does not address the question of which values and views should be taken into account and respected. Paper 6 (Cavaliere et al. 2019) looks at different approaches to answer this question and proposes a process of democratic engagement modelled on the framework of deliberative democracy and of the ‘well-ordered science’.

## 2 PAPER 5: A 14-Day Limit for Bioethics: The Debate Over Human Embryo Research

Paper 5 is a single-authored paper currently published in *BMC Medical Ethics*.

The original version of this paper is enclosed in Appendix 5.

Cavaliere, G. (2017). A 14-day limit for bioethics: The debate over human embryo research. *BMC Medical Ethics*, 18(1), 38, doi: 10.1186/s12910-017-0198-5

### 2.1 Abstract

#### Background

This article explores the reasons in favour of revising and extending the current 14-day statutory limit to maintaining human embryos in culture. This limit is enshrined in law in over a dozen countries, including the United Kingdom. In two recently published studies (2016), scientists have shown that embryos can be sustained in vitro for about 13 days after fertilisation. Positive reactions to these results have gone hand in hand with calls for revising the 14-day rule, which only allows embryo research until the 14<sup>th</sup> day after fertilisation.

#### Main text

The article explores the most prominent arguments in favour of and against the extension of the 14-day limit for conducting research on human embryos. It situates these arguments within the history of the 14-day limit. I start by discussing the history of the 14-day limit in the United Kingdom and the reasons behind the decision to opt for a compromise between competing moral views. I then analyse the arguments that those who are generally in favour of embryo research put forward in support of extending the 14-day rule, namely (a) the argument of the beneficence of research and (b) the argument of technical feasibility (further explained in the article). I then show how these two arguments played a role in the recent approval of two novel techniques for the replacement of faulty mitochondrial DNA in the United Kingdom. Despite the popularity and widespread use of these arguments, I

argue that they are ultimately problematic and should not be straightforwardly accepted (i.e. accepted without further scrutiny). I end by making a case for respecting value pluralism in the context of embryo research, and I present two reasons in favour of respecting value pluralism: the argument of public trust and the argument of democracy.

### Conclusion

I argue that 14-day limit for embryo research is not a valuable tool despite being a solution of compromise, but rather because of it. The importance of respecting value pluralism (and of respecting different views on embryo research) needs to be considered in any evaluation concerning a potential change to the 14-day rule.

**Keywords:** Embryo research | Value pluralism | Compromise | Beneficence | Warnock Report

## 2.2 Introduction

In August 2016, in a letter in *Nature* and in an article published in *Nature Cell Biology*, two groups based in different research centres in the United Kingdom (Cambridge and London) and in the United States (The Rockefeller University, New York) presented the results of their experiments on in vitro human embryos. For the first time, the embryos were sustained in vitro for 12-13 days after fertilisation (Deglincerti et al. 2016; Shahbazi et al. 2016). Prior to this, scientists were only able to sustain embryos in vitro for about seven days (Hyun et al. 2016).

Many members of the scientific and bioethics communities reacted enthusiastically to these advances, due to the novelty of the results and to the potential benefits that they could bring about (Connor 2016; Harris 2016b; Hyun et al. 2016). Research involving human embryos allows us to increase our understanding of the first stages of embryo development and it is considered instrumental to shedding light on the causes of early miscarriages, of problems related to infertility and of birth defects (Devolder 2015). In addition to this, embryo research has been instrumental to the development of human embryonic stem cells, cells derived from embryos have proved to be clinically useful to cure certain degenerative diseases (de Wert &

Mummery 2003; Devolder 2015; Mertes & Pennings 2009). Sustaining embryos *in vitro* for a longer period of time could allow an even greater understanding of the causes of embryo defects and early miscarriages, and it could prove especially clinically beneficial for women who have experienced multiple early pregnancy losses. Due to the current benefits of embryo research and to the potential future benefits of it, the positive reactions to these experiments went hand in hand with a call for revising and extending the so-called 14-day rule. This rule allows research involving human embryos up until the 14<sup>th</sup> day after fertilisation, a statutory binding limit in over a dozen countries (Hyun et al. 2016; Isasi & Knoppers 2006).

This article explores the arguments for and against extending the 14-day limit for research on human embryos. In the following section, I will briefly present the history of how the 14-day rule came about in the United Kingdom and the reasons behind the decision to opt for a solution of compromise. In section 3, I will discuss the arguments that those who are generally in favour of embryo research put forward in support of extending the 14-day rule, namely the argument of the beneficence of research and the argument of technical feasibility (further explained below). I will show how these two arguments played a role in the process that led to the approval of mitochondrial replacement techniques in the United Kingdom. In section 4, I will discuss why I find these arguments wanting. In the last section (5), I will present two arguments in favour of compromise, namely the argument of trust and the argument of respect for value pluralism. I will conclude that the importance of respecting value pluralism needs to be taken into account in any evaluation concerning a potential change of the 14-day rule.

### 2.3 The 14-Day Limit and the Warnock Report

The publication of the aforementioned two articles in *Nature* and *Nature Cell Biology* triggered a resurgence of the debate on embryo research and on the 14-day limit to carry out research on in-vitro human embryos. The 14-day limit came about in the United Kingdom at the beginning of the 1980s. Its birth is closely linked to another, non-metaphorical, British birth: the first test-tube baby (i.e. a baby conceived via in-vitro fertilisation), Louise Brown, was born in the United Kingdom in 1978. As noted

by historian Duncan Wilson, after the initial excitement surrounding Louise Brown's birth, public attitudes towards IVF shifted from an initially more favourable stance to a more critical view of the practice (Mulkay 1997; Wilson 2011; Wilson 2014). These predominantly negative attitudes, and the necessity to decide upon the fate of embryos 'left over' after IVF procedures<sup>164</sup>, contributed to calls for a tighter oversight of the practice. They also underscored the importance of deciding whether it was permissible to use these spare embryos for research (Mulkay 1997; Wilson 2011; Wilson 2014).

At that time, embryo research was the most debated matter concerning the ethics of IVF (Hammond-Browning 2015; Harris 1985; Warnock 1985a). Two conflicting positions dominated the public debate: on the one hand, those of whom were outright against embryo research. On the other, those of whom were in favour of doing research on embryos up until it was technically feasible. The first group appealed to the need to respect human life from its very beginning and argued that life starts in the moment of fertilisation (i.e. when sperm cells fertilise oocytes) and must be protected. Interestingly, not all the opponents of embryo research holding the view that embryos are persons were arguing from a religious standpoint (Hammond-Browning 2015). Some of those arguing against embryo research in principle referred to the potentiality of the embryos to become fully developed persons and concluded that human life, no matter at what stage of development, should be granted full protection, and that embryos should not be used for research (Donald 1984; George & Lee 2009; Jones 2011). The opposing view, held by those in favour of legalising embryo research, found support from those appealing to the potential benefits of such research, and from those who granted inexistent or low moral status to the embryos. This group also referred to the potentiality of embryos to become fully developed persons, but concluded that potential persons (i.e. embryos) were different from actual persons and that this was a sufficient reason to allow research on human embryos (Harris 1985). Unsurprisingly, according to them, the potential benefits of such research, for instance an increased understanding of

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<sup>164</sup> These embryos are not implanted in utero but frozen for further implantation. When a successful pregnancy is established, it had to be decided what do with these supernumerary frozen embryos.

early human development, better IVF procedures, and treating infertility and pregnancy losses outweighed the costs of embryo research (Harris 1985).

There are some differences between the 1980s debate on embryo research and today's newly emerged debate. Perhaps, the main difference is that, whereas previously research beyond the 14-day mark was scientifically untenable, it has recently become technically possible. When the limit was decided upon, scientists were not able to keep the embryos alive in vitro for longer than the limit allowed. The experiments reported in the two recent articles prove that scientists are now able to keep embryos alive for up to 12-13 days and possibly longer. In addition, IVF as an assisted reproductive technique has significantly improved and many of the technical advances in this technique are owed to embryo research. It is in this sense that, while the 1980s debate focused on the question of whether embryo research should be allowed, the current debate occurs against the backdrop of the advances that allow embryo research to be made possible. Thirdly, while in the past it was not possible to preserve the viability of the embryos employed for research, today there are technical solutions that allow scientists to obtain embryonic stem cells for research that do not result in the destruction of the embryo (e.g. embryo biopsy<sup>165</sup>). Lastly, whilst previous research was carried out on early human embryos only, today, and potentially increasingly in the future, embryo research could be done on artificial entities that bear sufficient resemblance to embryos to be suitable for such research. To name a few methods, these entities would be created through, for instance, altered nuclear transfer (ANT) or parthenogenesis of oocytes (de Wert & Mummery 2003; Devolder 2015; Hurlbut 2005)<sup>166</sup>.

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<sup>165</sup> For a detailed analysis of this alternative and of its limits, see the work of Devolder (2015).

<sup>166</sup> It must be noted that these two alternatives have been criticised for a number of reasons. For instance, it is unclear whether parthenotes are significantly different from human embryos and whether ANT really escapes the ethical challenges of embryo research and whether it is a scientifically realistic alternative (Devolder 2015).



### 2.3.1 Conflicting Moral Views on Embryo Research

Today's discourses on the moral status of human embryos are not so different from the discourses that, in the 1980s, resulted in the establishment of the *IVF Inquiry*, a committee appointed to produce an advisory report on the moral, legal and social issues raised by IVF, embryo research and other practices. Oxbridge philosopher Mary Warnock was appointed its chair. As I will show in the next sections, the procedural work of the committee, the views of the chair and the way the recommendations on how to proceed about embryo research were drafted, represent an important precedent for the current debate on embryo research.

The members of the committee, including Warnock herself, were aware of the conflicting moral views on embryo research, and of the difficulty of reconciling them and establishing which one should prevail (Department of Health and Social Security 1984; Warnock 1985b; Warnock 1988). In addition to this, they tried to review as many different points of view as possible: the committee considered evidence from experts working in the field of human reproduction (around 300 individuals and organisations) as well as from the public (695 letters and submissions). Although the evidence collected in this way was never published<sup>167</sup> and although it was never made transparent how this evidence influenced the final recommendations, it is presumed that the committee considered all the submitted evidence and took into account the different views that it reflected (Hammond-Browning 2015).

Legitimising embryo research would have likely caused uproar from those who accorded full moral status to human embryos. At the same time, an outright ban on embryo research was perceived as problematic for two reasons: due to a concern for the loss of potential benefits of embryo research, and due to the perceived need to allow IVF to go forward only if backed up by studies on the development of early human embryos. A solution to this impasse was to find a compromise between these two positions: this is how the idea to introduce a cut-off point until which research

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<sup>167</sup> The submissions from the experts can be found at the House of Commons Library, but they have never been published.

would be permissible came about. Introducing a cut-off was a solution of compromise, as it would have enabled embryo research, but only until a certain stage of development. Different possible limits were examined, including the 5<sup>th</sup> day (i.e. beginning of implantation in utero) and the 11<sup>th</sup> day (i.e. the end of implantation) after fertilisation.

It was developmental biologist Anne McLaren, a member of the committee, who proposed using a peculiar biological event in the embryo development to mark the end of the permitted period of research (Wilson 2011). McLaren suggested limiting research to the 14<sup>th</sup> day of development because this moment signals the emergence of the primitive streak in the human embryo, a precursor of the brain and the spinal cord. At the same time, the emergence of this streak marks the beginning of gastrulation, a process whereby the embryonic inner cell mass starts to differentiate into three layers (endoderm, mesoderm, and ectoderm). This process also corresponds to the last point in which the embryo could cleave into twins (i.e. twinning) or in which two embryos could merge into one (e.g. tetragametic chimerism). McLaren argued that: “If I had to point to a stage and say ‘This is when I began being me’, I would think it would have to be here” (McLaren 1984). In order to endorse the 14-day limit and the decision to allow research up until this stage of embryo development, the term ‘pre-embryo’ was coined. It designated the embryo before the emergence of the primitive streak, and it marked a distinction from the ‘unborn child’ (i.e. the embryo after the 14-day) (McLaren 1984; Wilson 2014). It was therefore a term with ethical and political significance, a term that designated the boundary between acceptable and non-acceptable research.

Eventually, in 1990, the recommendations of the IVF-Inquiry comprised in the Warnock Report (Warnock 1985b) were enshrined into law, in what became the Human Embryology Act (Department of Health and Social Security 1984).

### **2.3.2 How the 14-day limit came about: compromise and its critics**

Introducing a cut-off date –in this case the 14-day limit – represented an instance of favouring compromise between competing moral views, beliefs and values over questions of rightness and wrongness (Franklin & Roberts 2006; Hammond-

Browning 2015; Mulkay 1997). Questions regarding whether or not the embryo has moral status, what moral status stands for and entails, and questions regarding the core features of personhood and the beginning of human life were overridden by other considerations. These considerations included the moment from which the embryo should be granted legal protection, what kind of society can be praised and in what kind of society people can live with clear conscience (Warnock 1985a; Wilson 2014). The decision to shift the focus from ontological questions concerning rightness and wrongness to more practical questions is linked to a conception of morality whose role is to address moral matters arising in the context of public policy, and to the role that the committee was created to fulfil. The IVF-Inquiry was not created to produce perfect philosophical reasoning and give a lesson in moral expertise, but rather to facilitate a process whereby scientists' work would become more "socially palatable" and whereby workable regulations would be delivered (Anon 1983; Wilson 2014).

The committee favoured a moral relativistic approach to embryo research and to the conflicting positions present in the debate. Instead of trying to establish which position was the most accurate one and what view came closest to an absolute moral truth, the committee worked under the assumption that the views of those for and against embryo research deserved to be equally respected and taken into consideration. Thus, the view of those who believed that the embryos are to be treated as if they were persons (and hence, they deserve full moral status) and research on them should be banned, and the view of those who believed that embryos are not more than a cluster of cells (no moral status at all) and research on them should go forward were equally taken into account. In this sense, the committee followed the assumption that the truth and standing of moral judgments is not universal, but relative to the social, political and cultural context in which these moral judgements arise (Gray 1998). Warnock and her committee experienced first-hand the diversity of views both in her committee and in society at large. Their strategy was to exercise tolerance in matters of morality and moral disagreement, and to respect value pluralism (Warnock 1983; Warnock 1985a). Warnock understood the role of her committee in these terms: starting from the acknowledgement of the different and competing moral positions, she tried to find

the path of greater social consensus among them (Mulkay 1997). In addition to this, Warnock and her committee opted to take into account not only moral arguments based on scientific evidence and philosophical reasoning, but also moral feelings and beliefs (Jones 2011). In this sense, they followed Hume's idea that feelings, and not pure calculating rationality, need to be considered in the assessment of ethical dilemmas and that morality is 'more properly felt than reasoned' (Blackburn 1998; Hume 1738/2006).

Perhaps unsurprisingly, given the existing disagreement on the matter, the committee recommendation to allow embryo research up until the 14<sup>th</sup> day was highly criticised. Three committee members were outright against embryo research and refused to endorse the final recommendations concerning this matter (Hammond-Browning 2015; Warnock 1985b). Members of the conservative party, of the pro-life group LIFE and Christian scientists such as Ian Donald, publicly criticised the decision and lobbied against the report recommendation during the parliamentary debate on the matter (Hammond-Browning 2015; Wilson 2014). Generally, reactions from the more conservative side of the debate opposed this solution because it employed a sort of utilitarian calculus (i.e. the potential benefits of embryo research) instead of foregrounding considerations concerning how we ought to treat unborn persons.

Interestingly, both those against and in favour of conducting research on human embryos agreed on some of the reasons why the 14-day limit was at least problematic, if not completely wrong, namely arbitrariness and dodging the most fundamental question. Those that criticised the decision on the grounds of its arbitrariness argued that it was impossible to draw a morally and legally significant distinction between an embryo that was 13, 14 or 15 days old. However, supporters and critics of embryo research drew different conclusions from this impossibility to draw morally consistent lines: supporters argued that embryo research should have been allowed until it was technically feasible (i.e. until when the scientists could keep the embryo alive in vitro), while critics argued that embryo research should have been banned altogether. Another point of convergence between supporters and critics was the fact that Warnock and her committee did not address the questions

of when life begins and when an embryo becomes a person. The decision to focus instead on the legal and moral rights of the embryo, without addressing the issue of what an embryo really is, was seen as extremely problematic by both sides. According to them, it was impossible to decide whether or not the human embryo deserved protection without establishing why it/she/he deserved protection, in other words whether or not the embryo was a person (Harris 1985; Jones 2011).

In addition to these critiques, philosopher John Harris criticised Warnock and the committee for taking into account people's feelings. Harris argued that not all feelings were moral feelings and not all of them deserved respect. According to him, moral feelings should be evaluated on their capacity to make the world a better place, to save lives and postpone deaths (Hammond-Browning 2015; Harris 1985).

These reactions are important because they show that, back then as today, there is indeed a fundamental moral disagreement concerning early human life, how to treat human embryos and about the legitimate role of feelings and passions in public and regulatory discourses (Gottweis & Prainsack 2006). The reactions that followed the committee's recommendations show the extent to which these views were in fact incompatible. However, it is important to note that those who criticised the decision on the grounds of arbitrariness and inconsistency in a certain sense missed the point of the role and function of the committee. The committee was put together in the first place in order to maintain public trust and be a reliable means for external oversight of scientific research. For this reason, the recommendations were meant to be a solution of compromise rather than a means to find the most consistent moral view.

In the next section, I will briefly outline the reasons that advocates of embryo research currently put forward in favour of extending the limit, and show how these same reasons have played an important role in the debate on whether to introduce two new techniques into the clinic.

## 2.4 The Reasons in Favour of Extending the Limit

Scientists (Robin Lovell-Badge and Azim Surani quoted in Connor 2016) and ethicists (Harris 2016b; Hyun et al. 2016) reacted to the results reported on *Nature* and *Nature Cell Biology* by publicly calling for an extension of the 14-day limit and for revising the current regulation of embryo research. The argument that they used strikes familiar chords: embryo research is beneficial and now technically possible, therefore it should be allowed. The two publications in *Nature* and *Nature Cell Biology* (Deglincerti et al. 2016; Shahbazi et al. 2016) partially changed the narrative of the debate on embryo research: whereas in the 1980s it was a matter of legalising such research, today the debate is about extending the 14-day limit for reasons grounded in beneficence and technical feasibility, and thus merely adjusting the regulatory framework of an already legalised practice. These reasons draw upon consequentialist premises and the principle of utility. They imply that being able to carry out potentially beneficial research and not doing so would be morally impermissible<sup>168</sup>.

According to the advocates of embryo research, the reasons in favour of extending the 14-day limit are stronger today than they were in the past. In 1984, these reasons relied on positive provisions of the potential benefits (i.e. the beneficence of research) and positive provisions of the future feasibility (i.e. technical feasibility). In the past, it was about faith in science and managing the uncertainties of potential future benefits of embryo research with certain regulations. Today, Harris, Lovell-Badge and Surani argued, it is about certainties concerning the benefits and certainties of technical feasibility: embryo research has proven to be both beneficial and feasible (Connor 2016; Hyun et al. 2016).

The use of beneficence and feasibility in the debate on technical innovations recalls another debate where similar arguments have been advanced in response to scientific breakthroughs. Early in 2015, the United Kingdom became the first country in the world to allow two novel techniques that allow women with

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<sup>168</sup> I have commented elsewhere that this line of argument is problematic (Camporesi & Cavaliere 2016).

mitochondrial DNA diseases to have genetically related children with a decreased risk of developing mitochondrial diseases. Mutations in the mitochondrial DNA are the cause of many diseases including, for instance, mitochondrial myopathy, Leigh disease and diabetes mellitus, and they are normally inherited through the maternal line (Bredenoord & Braude 2010). Up until the approval of these two techniques, prospective mothers needed to turn to oocytes donors, PGD or adoption in order to have children free from these genetically inherited mutations (Bredenoord et al. 2008). Although these techniques (maternal spindle transfer, MST, and pronuclear DNA transfer, PNT) have been depicted as involving the ‘replacement’ of the affected mitochondrial DNA of the oocyte of the prospective mother or of the fertilised oocyte with the mitochondrial DNA of a female donor, this description is inaccurate. What really happens is that the oocyte’s, or zygote’s, nucleus previously housed in a cell with deleterious mitochondria is rehoused in an enucleated cell with healthy mitochondria. The embryo that results from these techniques will have the genetic makeup of the prospective father, the mitochondrial DNA of a donor and the nuclear DNA of the prospective mother.

Despite the similarities between the arguments in favour of the extension of the 14-day limit and the arguments in favour of allowing mitochondrial replacement techniques (MRTs), it is important to note that there are differences between the current debate on extending the limit for embryo research and the recent debate on MRTs<sup>169</sup>. These differences concern both the *content* of these debates (i.e. the specific arguments in favour and against and the object of the controversy) and their potential *outcomes* (i.e. extending an existing limit for embryo research instead of allowing two new techniques to be introduced into the clinic). With respect to the content, the arguments against MRTs focused on concerns regarding the implementation of newly developed techniques and the risks that their implementation may pose to future children. On the contrary, the arguments against the extension of the 14-day limit focused on basic research rather than clinical implementation. In particular, they pertain to the ethics of using intrinsically

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<sup>169</sup> I am grateful to one of the anonymous peer reviewers for raising this point.

valuable beings such as human embryos for instrumental purposes. In addition, these debates differ in terms of what proponents and opponents wanted to achieve (i.e. in terms of outcome). The potential outcome of the debate on MRTs was to establish whether these new techniques were sound from a technical and moral point of view. On the contrary, the debate on embryo research is about setting a new limit for continuing existing research and for possibly gaining new insights into embryo development. These are just a few of the differences between the two debates and a detailed analysis of such differences is beyond the scope of this article. However, it is important to note that despite these differences, some similarities with respect to the argument in favour of MRTs and embryo research can be drawn. In particular, arguments in favour of MRTs and of extending the 14-day limit were inspired by beneficence and technical feasibility in both instances.

One of the most contested issues concerning the ethics of MRTs is whether these techniques would bring about changes to the human germline (i.e. changes in human oocytes, sperm cells or embryos that do not only appear in the children resulting from the procedure, but also in succeeding generations) (Newson & Wrigley 2017). Ethicists and scientists are divided over whether MRTs amount to germline modifications as changes introduced in the oocyte (in the case of MST) or in the zygote (in the case of PNT) concern the mitochondrial rather than the nuclear DNA (Adashi & Cohen 2016). In addition, as mitochondrial DNA is inherited from the maternal line, if only male embryos are transferred in utero, the modifications introduced with MRTs will not be present in the succeeding generations<sup>170</sup> (Newson et al. 2016). An assessment of these arguments is beyond the scope of this article<sup>171</sup>, but what matters for the present analysis is that up until the approval of these techniques, modifications of the genetic makeup of sperm cells, eggs and

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<sup>170</sup> In the United Kingdom, the law regulating MRTs allows both female and male embryos to be transferred in utero. This is different from the American approach to the clinical implementation of these novel techniques: the National Academies of Science, Engineering and Medicine (NASEM) Report recommended that only male embryos should be implanted in utero (National Academies of Sciences Engineering and Medicine 2016; Newson et al. 2016).

<sup>171</sup> For insightful analyses of the MRTs debate and of the ethics of these techniques, see (Appleby 2015; Bredenoord et al. 2009; Herbrand 2017; Palacios-González 2016; Rulli 2017; Wrigley et al. 2015).



embryos were only legally possible in-vitro and never for clinical purposes in-vivo. Modification of the human germline (i.e. gametes, and embryos) has traditionally been considered a line that should not be crossed. This line was recognised as morally relevant in 1978 with the publication of *Splicing Life*, a report of the US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research appointed to regulate gene therapies, the reasons given were partly scientific (i.e. it was not technically feasible) and partly moral (i.e. it was seen as immoral to introduce changes that would have been inherited by future generations) (Addison 2016; President's Commission 1982). Modifying the human germline is seen as problematic because of the unforeseen effects on future generations, the risk of engaging in a form of new eugenics, the risk of sliding down a slippery slope to human enhancement, and other similar arguments (Anderson 1985; Anderson 1989; Fletcher 1985). These arguments were already put forward at the very early developments of gene therapy and rehearsed in recent debates on MRTs and gene editing (Adashi & Cohen 2016). However, both historically and more recently they have not remained unchallenged. Questions related to eugenics, enhancement and unforeseen effects on future generations have been widely discussed during the months prior to the approval of MRTs and they are still a matter of ethical inquiry, as shown by the increasing number of articles and reviews that address these issues (Palacios-González 2016; Rulli 2016a; Wrigley et al. 2015; Nuffield Council on Bioethics 2012). In addition, the public consultation (2012) and the extensive reviews of the scientific methods of MRTs carried out by the HFEA (respectively in 2016, 2014, 2013, 2011), the work of the Nuffield Council<sup>172</sup> (Nuffield Council on Bioethics 2012) and the parliamentary debate on these techniques have considered such concerns. As briefly outlined above, it is only with some caveats that MRTs can be considered a break with the past. However, even considering these caveats, the 2015 approval of these techniques by the UK Parliament could be seen as a first instance of crossing an internationally recognised ethical and legal limit due to reasons of beneficence (i.e. children born with these

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<sup>172</sup> The Nuffield Council on Bioethics is an UK-based independent institution that examines ethical issues arising in the field of biotechnology and biomedicine.

techniques will be free from mitochondrial diseases), but also due to the technical feasibility of germline modifications (prior to the parliamentary vote on MRTs, these techniques were not considered safe enough to be introduced into the clinic) (Newman 2013; Newman 2014). It is in this sense that the sum of the arguments in favour of extending the 14-day limit echoes, albeit only partially, those in favour of allowing MRTs. Mitochondrial replacement techniques represent an interesting case study and set an important precedent for the ethical assessment of technical innovation. In contrast with other instances of internationally recognised bans such as the ban on human cloning, the approval of MRTs shows that long-standing limits such as the ban on germline modifications can be redefined once scientific advances make it possible. The argument of beneficence to allow research on human embryos for longer than 14 days is the same as the one made in the 1980s. What has changed is that while before it was technically difficult to introduce changes in reproductive cells and embryos that would be inherited by future generations, and to keep the embryos alive in vitro for a longer time span, now both actions are theoretically possible. The question, therefore, is whether the potential benefits of embryo research and the feasibility of keeping the embryos alive for longer than ever before are sufficient reasons to extend the limit.

## **2.5 There Is More to Beneficence and Technical Feasibility Than Meets the Eye**

In this section, I will show that technical feasibility and beneficence of research as reasons in favour of extending the limit of embryo research are not as fundamental as those who advocate this change in the law claim. Accordingly, I scrutinise the arguments in favour of the extension of the 14-day limit, while I leave unchallenged those presented by the advocates of a more restrictive regulatory framework for embryo research. The rationale behind this choice does not rest on my own view on embryo research, as I do not necessarily share the beliefs and values of those against this practice. However, it is often argued by proponents of technological changes that the burden of justifying one's own claims rests solely on those who take a precautionary approach to technological progress (Giubilini 2015; Harris 2007; Hyun

2016). Against this view, I propose that both those in favour and against embryo research ought to share the burden of justifying their moral views.

### 2.5.1 Facts, Values and Rationality

Technical feasibility as a reason in favour of extending the limit relies (i.e. practice x is now technically feasible, so there are good reasons to change the rule) on the premise “practice x is technically feasible” to infer the conclusion “there are good reasons to change the rule”. However, appealing to the beneficence of research and to its technical feasibility is more problematic than those in favour of extending the limit for embryo research suggest it is. As a matter of fact, this line of arguing is problematic because it relies on what eighteenth-century philosopher David Hume considered an “inconceivable deduction” of what *ought* to be done from a set of *is*-premises (Hume 1738/2006). Hume believed that it was logically fallacious to infer a normative judgment (ought-conclusion) from a set of factual claims (is-premises). Thus, following Hume, the normative conclusion “there are good reasons to change the 14-day rule” cannot be rightly inferred from the factual premise “embryos can now survive in vitro for longer than before” (i.e. technical feasibility of extending the time span for embryo research). This critique of inferring normative conclusions from factual claims is similar to the critique that philosopher George Edward Moore moved to moral naturalists (i.e. those who argue in favour of a link between moral philosophy and the natural sciences). Moore argued that anyone who infers that practice x is good from any preposition about the natural properties of x commits the “naturalistic fallacy” (Moore 1903). According to Moore, this fallacy shows how premises about some factual or natural features of practices do not support normative conclusions about these practices. Thus, anyone who supports an extension of the 14-day limit for embryo research on the basis of the technical feasibility of this research would commit the naturalistic fallacy. According to Moore, one of the main problems of moral naturalists was that they relied on purely factual premises concerning the natural features of certain practices to infer normative conclusions concerning these practices. To counter this tendency, Moore suggested instead that

normative conclusions ought to be inferred from both factual and normative premises.

The argument of the beneficence of research (i.e. embryo research should be allowed for longer than 14 days due to the benefits of such research) is also more problematic than those in favour of extending the limit suggest it is. According to this argument, the 14-day limit should be extended because of the potential benefits of such research and because these benefits outweigh the costs of embryo research (Devolder & Savulescu 2006; Douglas & Savulescu 2009; Harris 1985; Harris 2016b). This appeal to beneficence is common in bioethics and it is often used by those who take a utilitarian stance on the ethical assessment of scientific progress, technologies and practices (Harris 1992; Harris 2007; Hyun et al. 2016; Savulescu 2005; Savulescu & Kahane 2009). Proponents of what I have called the argument of the beneficence of research rely on historical evidence to support their claim: they argue that since technological and scientific progress in medicine proved to be beneficial to humankind, it should be allowed to continue. Returning to embryo research, those who appeal to the beneficence of research to extend the 14-day limit ground their argument on the past benefits that embryo research brought about, and on the potential benefits that the extension of the limit could bring about (Connor 2016; Harris 2016b).

At first sight, it seems fairly obvious that if something is beneficial, even only potentially beneficial, it should be allowed. However, this approach is problematic for a number of reasons and scholars have criticised bioethicists, institutions and scientists for their often-hyped claims concerning the benefits of new technical possibilities (Árnason 2015; Hedgecoe 2003; Hedgecoe 2010; Marris 2015). Firstly, the argument of beneficence and its proponents rely on an optimistic view of scientific progress, research and technologies (Árnason 2015; Elliott 2005; Salter & Salter 2007), a view that echoes the post-illuminist positivistic ideas of science and technology, and that often overemphasises the potential benefits of scientific research (Elliott 2005; Hedgecoe 2010; Marris 2015) and its understating as a progressive and linear endeavour (Camporesi & Cavaliere 2016; Williams 2006). Secondly, the argument is problematic because it relies on a misleading estimation

of costs and benefits. The benefits taken into consideration for the cost-benefit assessment are not the benefits of embryo research for the embryos, as embryo research does not benefit embryos. Instead, the benefits considered are those to society, to existing and future individuals. On the contrary, the costs taken into account for the cost-benefit assessment are not those to society, but to the embryos used for research. Those who emphasise benefits of embryo research over its costs do not grant moral status to the embryos, nor do they believe that embryos are capable of experiencing pain (i.e. being harmed). Hence, they do not really see any cost associated with embryo research, and they thus conclude that benefits outweigh these (inexistent) costs. The substantial disagreement over the moral status of the embryos and the criticism moved against research on human embryos show that embryo research is a controversial and not-settled issue (Hammond-Browning 2015; Selgelid 2001). For this reason, the costs of extending the limit beyond the 14<sup>th</sup> day, and of embryo research more generally, might be higher than proponents of embryo research like to admit. Embryo research has a societal cost of offending certain moral feelings on the value of early human life, and not respecting certain strongly held convictions on how we ought to treat human embryos. Thus, individuals who hold such views may find themselves feeling alienated from or devalued by society (Deckers 2005; George 2009; Jones 2011). Possibly, proponents of embryo research who argue from a utilitarian standpoint, and who rely on the argument of the beneficence of such research, are aware of the possibility of offending moral feelings and strongly held beliefs, but they still consider the benefits of embryo research greater than the costs of offending the people who hold these feelings.

One of the reasons why many proponents of embryo research do not grant moral worth to these feelings, and to the opponents' arguments, is that they consider their views to be fundamentally flawed, irrational and not grounded in scientific evidence. Most advocates of embryo research thus dismiss the view that embryos are (future) persons and that embryo research would violate these future persons' dignity on the grounds of the irrationality of such ontological claims. For to them, these claims are based on faith rather than reason and factual considerations. However, it is important to note that those in favour of embryo research who argue from supposedly rational positions do not live up to the very same standards of rationality

that they require of their opponents. In this sense, dismissing questions related to human dignity and the moral status of the embryos on the basis of their irrationality and lack of scientific support, becomes problematic (Guyer & Moreno 2004; Hedgecoe 2010). Scientific evidence is often interpreted according to one's own pre-existing moral convictions, so-called evidence-based claims are still influenced by these moral convictions and by the way bioethicists react and argue about new technical possibilities (Borup et al. 2006; Hedgecoe 2010; Swierstra & Rip 2007). Thus, irrational beliefs are not an exclusive ownership of those arguing against embryo research: similar irrational beliefs play a role in assessments of embryo research put forward by those in favour of embryo research on the grounds that it can save future lives<sup>173</sup>.

### 2.5.2 Slippery Slope

The slippery slope argument offers a last reason of caution against embryo research (Freeman 1996; Macklin 1994; Sandel 2004b). The slippery slope argument entails that allowing practice x (in this instance, allowing embryo research or extending the limit for embryo research) would initiate a process leading to unethical practices w, y, z. The slippery slope argument against embryo research is approximately like this: embryo research should not be allowed/the limit should not be extended because allowing research on embryos in a very early stage of their development/extending the limit beyond day 14 will lead to the permissibility of research on fetuses and new-borns. The argument voices the concern that once we become accustomed to research on pre-embryos, we will extend the permission for research on embryos on a later stage of development; once we become accustomed to this too, then we will allow research on fetuses and babies. 'Slippery slopers' believe that morally problematic practices such as embryo research should not be allowed, or the limit should not be extended, because of the difficulties of drawing a line between practices currently considered less morally problematic, such as research on pre-

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<sup>173</sup> For a detailed discussion of such position in another context (i.e. the debate on human enhancement), see (Giubilini 2015).

embryos, and practices currently considered highly immoral, such as research on foetuses at a late stage of their development. These arguments are widely criticised in the philosophical arena for their lack of empirical evidence, and for not considering that government regulations can be used to prevent such scenarios from coming into being (Caplan 2005; Resnik 1994; Walton 1992). In spite of these critiques, they are still used in debates on technological advances, scientific research and policy making (Darnovsky 2013; Freeman 1996; Sandel 2004b; Swierstra & Rip 2007). The persistence of slippery slope arguments in academic works and policy making seems to suggest that attempts from philosophers to discredit this argument have been unsuccessful. The charge of starting a slippery slope towards inadmissible practices is still a powerful one (Selgelid 2001; Swierstra & Rip 2007). An analysis of the theoretical fallacies and merits of this argument is beyond the scope of the paper, as is a final assessment of its validity. However, it is important to note that extending the limit beyond the 14<sup>th</sup> day of development will provide support to those who rely on the slippery slope argument to oppose embryo research. This might have non-negligible social consequences. For example, extension of the limit for embryo research would show that what is feared by ‘slippery slopers’ (i.e. that once a practice becomes legal it is difficult to prevent the permission of its future developments) can eventually become a reality. Even if the limit was extended only for a few days, ‘slippery slopers’ might take this extension as a sign that their fears are well grounded, contrary to what their critics argue.

## **2.6 Is Compromise the Best Way Forward?**

Let me take stock of what I have said thus far. In the previous section, I have shown how the arguments of beneficence and technical feasibility in favour of embryo research and of extending the 14-day limit are less straightforward than their proponents seem to suggest. I have also suggested, using the slippery slope argument as an example, that extending the limit for embryo research might undermine public trust in scientists, regulators and overseeing bodies. In order to show the importance of compromise and the value of respecting pluralism in the context of embryo research, I will not juxtapose the arguments of the beneficence of research and of

technical feasibility with arguments pertaining to the sanctity of human life and human dignity. These arguments arise in the context of fundamental disagreements concerning the beginning of human life, the value of personhood, and concerning what respect human dignity ought to entail. They are portrayed as factual questions by both advocates and critics of research (i.e. research beyond the 14-day should not be allowed/should be allowed because human embryos *are/are not persons* and doing research on them would/would not violate their dignity); however, they are not merely a matter of fact, but they are informed and shaped by values, feelings and beliefs. Regardless of one's opinion regarding the values and beliefs of those defending the sanctity of life view, the burden of justifying one's claim should rest both on those defending this view and on those advocating technological progress, contrary to what seems to be normally believed (Giubilini 2015).

What I intend to argue in this last section is that even if the question of the moral status of the embryos cannot be easily settled, there are two arguments in favour of reaching a compromise and respecting value pluralism in the context of embryo research: the argument of trust and the argument of respect. I will argue that the argument of trust in favour of compromise, albeit being sound and widely used, could, in certain instances, assume instrumental and paternalistic forms. I will then argue that in the context of embryo research and more generally in the governance of scientific and technical breakthroughs it would be helpful to employ another argument: what I call the argument of respect.

### **2.6.1 The Argument of Trust and the Argument of Respect**

The first argument in favour of reaching a compromise that, other things being equal, respects value pluralism is what I define as "the argument of trust". It is structured as follows:

- a) Scientific research is important because it improves people's lives and it should be allowed to carry on
- b) Public trust is necessary to carry on scientific research
- c) Therefore, public trust in scientific research ought to be preserved



Given competing views concerning the moral status of the embryo, this argument provides a reason in favour of finding a solution of compromise that accommodates as much as possible these views and avoids the risk of overriding those of one camp with those of the other. The argument of trust relies on premise a) to show that people's lives are improved by scientific research (Savulescu et al. 2015). It relies on premise b) to show that public trust is a necessary condition for scientific research to be carried on (O'Neill 2002; Resnik 2011). Trust is needed to ensure public acceptance of concrete applications of research; to preserve public confidence in policies informed by scientific research; and to allow the investment of public resources in scientific research (O'Neill 2002; Resnik 2011). In the context of embryo research, the argument shows that, given the potential benefits of embryo research (premise a), and given the importance of public trust to carry on this type of research (premise b); there are good reasons to preserve public trust (conclusion c). Following this argument, it is possible to draw two conclusions: on the one hand, if the extension of the 14-day limit for embryo research is strongly opposed by the public<sup>174</sup>, then there are good reasons not to extend the limit. On the other, if opposing views coexist in the public understanding of embryo research, then there are good reasons to find a solution that strikes a compromise between these views.

The 14-day limit was a solution of compromise between conflicting moral views designed to maintain public trust whilst allowing research to go forward (Franklin & Roberts 2006; Warnock 2002; Wilson 2014). Today, there are two questions that need to be addressed, an empirical and a normative-theoretical question. The empirical question is whether the public (or at least a vast majority of it) is against the extension of the 14-day limit for embryo research. The normative-theoretical question is whether public opinion should influence the decision to change or retain the current 14-day rule, and if so, to what extent. An implication of taking into account the empirical question is that, if the public view of embryo research has become more favourable, then there is at least one good reason in favour of revisiting

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<sup>174</sup> It must be noted that the idea that 'the public' is against scientific developments and breakthroughs is criticised for being artificially constructed (see for instance: Marris 2015).

the 14-day rule<sup>175</sup>. In January 2017, a YouGov poll commissioned by the BBC in the United Kingdom, asked respondents' views on an extension of the limit up to the 28<sup>th</sup> day. Interestingly, 48% of the 1,740 respondents said that they would be in favour of extending the limit, while 19% wanted to keep the current limit. In addition to these respondents, 10% maintained that they would want embryo research to be banned altogether, while 23% did not express any of the aforementioned preferences (Leida 2017). In addition to the empirical question regarding public attitudes towards the extension of the 14-day limit, one may wonder how such attitudes would be towards therapies and scientific results obtained thanks to research on embryos beyond this limit in countries that may extend it. Currently, the 14-day limit is either enshrined in the laws (for instance in the United Kingdom, Canada and Spain) or specified in the scientific guidelines (for instance in Singapore, China and in the United States) of many countries. However, these regulatory frameworks may change in the future. Hence, if this becomes the case, it would be interesting to investigate public attitudes towards those therapies and other advances of basic research that are made possible by research in countries that allow embryo research beyond day 14<sup>176</sup>.

I will not provide an answer to these empirical questions here, if only because of the dearth of empirical data on public attitudes towards the extension of the limit, and embryo research more generally. Regarding, instead, the normative-theoretical question (i.e. whether public opinion should influence the decision to change or retain the current 14-day rule) the argument of trust would indicate that the answer is yes: public opposition to extending the 14-day rule should prevent its extension, while public agreement to a proposed change (i.e. the 28-day limit or other future proposals) should facilitate its extension. The risk of proceeding regardless of public attitudes towards an extension of the limit is that policies derived by embryo research will not be backed up by public consensus and applications of embryo

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<sup>175</sup> Other good reasons include technical feasibility, public utility and so forth.

<sup>176</sup> A case in point is Germany, which allows research on embryonic stem cells that are produced abroad (i.e. in countries with less restrictive legislations) before January 2002 (when the German Stem Cell Law was issued), but does not allow to derivation of stem cells from supernumerary embryos (Devolder 2015).

research (e.g. therapies developed thanks to the knowledge yielded by embryo research) not accepted. If the importance of maintaining public trust in scientific research (premise b) is motivated by these considerations, *then* it seems that public trust is only valued for instrumental and extrinsic reasons. In other words, this understanding of the importance of maintaining public trust in scientific research does not value public trust for its own sake, but only for its role in allowing research to go forward. What is problematic of this approach to public trust is that it offers a consequentialist reason in favour of respecting value pluralism, a reason that pertains to the better tangible outcomes of respecting value pluralism over other strategies of governance. In addition to this, when the instrumental justification of maintaining public trust is associated with a representation of the public as ill-informed and with little or no understanding of the potential benefits of research, it could be motivated by paternalistic considerations. Scientists and ethicists may risk misinterpreting public concerns and views over embryo research as the result of a lack of expertise or evidence-based information rather than a matter of legitimate and genuine disagreement over values (Hurlbut 2017; Marks 2009).

The second premise of the argument of trust, however, could be also motivated by a concern for a deliberative conception of democracy. This conception of democratic governance requires to both citizens and their representatives to provide public justifications of their views and to engage in deliberative processes. Public trust becomes then fundamental to allow these deliberative processes to take place and to foster better strategies for policy-making (Cohen 2003; Gutmann & Thompson 2009). These deliberative processes of mutual exchange between experts and the public, together with a commitment to respecting conflicting moral views (i.e. respect for value pluralism) provide a reason in favour of finding a solution of compromise that, given competing views concerning the moral status of the embryo, respect this plurality of views and values regarding embryo research. These considerations concerning the importance of maintaining public trust echo other considerations employed to defend democracy as a political system and as a valuable form of governance. These include, for instance, equality: given the existence of conflicting views, values and beliefs, a good reason to respect them is that people or groups holding these different views will be respected by being granted an equal say

on matters of common concern (Gutmann & Thompson 1996; Waldron 1998). Mertens and Pennings (2009) have argued in favour of the benefit of compromise in the context of different policies regulating embryonic stem cell research and have concluded that there is a moral obligation to respect conflicting moral views (Mertes & Pennings 2009). Similarly, Devolder argued that in spite of the epistemic costs of compromise, middle-ground positions could still be defended in the context of policy-making (Devolder 2015). What I suggest here is that the commitment to a democratic decision-making process entails a fundamental respect for value pluralism (Jasanoff et al. 2015). In Warnock's and the IVF-Inquiry's time, this respect for value pluralism translated into a deliberation resulting in the 14-day rule. Today it translates into favouring an assessment of the rule and of the potential reasons to change it that once again takes into account the conflicting moral views held in society; an assessment that cannot rest on the argument of the beneficence of research and of scientific feasibility alone.

## 2.7 Conclusions

In this article, I have argued that the 14-day limit for embryo research is not valuable *in spite of* being a solution of compromise, but rather *because of* it. The idea of a democratic society is that even those who do not accord intrinsic value to the human embryo should respect value pluralism and accord moral worth to opposing views. For this reason, any proposal to change the 14-day rule needs careful evaluation of the scientific feasibility and effective benefits of embryo research; it needs an extensive inquiry into public attitudes concerning embryos; and it needs a deliberative process that takes these elements into account. It does not need positions that consider only the beneficence of research and its technical feasibility. This would be undemocratic and potentially a move not backed up by a rigorous assessment of the science behind embryo research. Warnock and the other members of the IVF-Inquiry, albeit possibly guided by utilitarian-inspired views, opted for valuing a solution of compromise over other solutions (Chan 2015; Nelson 2005). They did so behind closed doors. In this sense, the recent experiments published in *Nature* and *Nature Cell Biology* and the newly sparked debate on embryo research

represent a valuable opportunity to begin a truly deliberative and democratic debate on this issue (Cohen 2003; Jasanoff et al. 2015). All in all, greater technical potential translates into greater responsibilities and need for deliberation.

## 2.8 Declaration

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### 3 PAPER 6: Regulating Genome Editing: For an Enlightened Democratic Governance

Paper 6 is a co-authored paper published in *Cambridge Quarterly of Healthcare Ethics*

The original version of this paper is enclosed in Appendix 6.

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Statement of contribution: I am the first author of this paper. I conceived the idea of using genome editing as a case study to discuss the question of how to regulate new technologies that generate moral disagreement after several conversations with AG. AG wrote the first draft of the introduction and of the section on the elitist approach and provided comments on the rest of the paper and especially on the shortcomings of the democratic approach. KD wrote the first draft of the shortcomings of the elitist approach and edited and provided extensive comments on the rest of the paper. I wrote the first drafts of the sections on the democratic approach and on the enlightened democracy approach and edited and provided comments on the rest of the paper, in particular the section on the elitist approach. We discussed and revised the paper several times.

#### 3.1 Abstract

How should we regulate genome editing in the face of persistent substantive disagreement about the moral status of this technology and its applications? In this paper, we aim to contribute to resolving this question. We first present two diametrically opposed possible approaches to the regulation of genome editing. A first approach, which we refer to as ‘elitist’, is inspired by Joshua Greene’s work in moral psychology. It aims to derive at an abstract theoretical level what preferences people would have if they were committed to implementing public policies regulating genome editing in a context of ethical pluralism. The second approach, which we refer to as the democratic approach, has been defended by Françoise

Baylis and Sheila Jasanoff et al. and emphasizes the importance of including the public's expressed attitudes in the regulation of genome editing. After pointing out a serious shortcoming with each of these approaches, we propose our own favoured approach—the 'enlightened democracy' approach—which attempts to combine the strengths of the elitist and democratic approaches while avoiding their weaknesses.

**Keywords:** Genome editing | Public engagement | Public policy | Democracy | Moral psychology | Moral pluralism

### 3.2 Introduction

With every significant scientific breakthrough that could have significant societal impacts, such as the development of a new biotechnology, ethical questions typically arise at two levels. At the first level, there are *substantive ethical* questions, such as questions regarding the moral status of the new biotechnology and the ethical dilemmas that may arise from its application. Questions at the second level pertain to how we should regulate this biotechnology, and who should decide about how to regulate it. We will refer to these as *ethical-political questions*.

Within society and among bioethicists, there is often significant disagreement at the level of substantive ethical questions, which is not surprising given that our views are influenced by highly diverse political, cultural, moral and religious beliefs. Persistent disagreement at this level is not necessarily problematic. Actually, the co-existence of fundamentally different ethical views is not only inherent to democratic societies (Gutmann & Thompson 1996) it is often considered essential for them to thrive (Mill 1859/1979). Arguably more problematic is disagreement at the level of ethical-political questions, as this could hinder the policy-making process and leave controversial biotechnologies unregulated, or regulated in a problematic way, e.g. in a way that alienates a large section of society (House of Lords 2000). This is, arguably, what happened with the regulation of genetically modified (GM) foods (Adam et al. 1999; Wynne 1996). Governments and scientists have been criticized for not taking the public's concerns about GM foods sufficiently seriously and for misidentifying the nature of their concerns, which then resulted in a lack of public

support for the development of this technology, and in a general mistrust in science (Adam et al. 1999; House of Lords 2000; Wynne 1996).

The recent debate on genome editing raises concerns previously discussed in the debates on GM foods and rDNA experimentation (Jasanoff et al. 2015), as well as new questions arising from its efficacy, precision and relatively low cost of application (Ledford 2015). The possibility of inserting heritable changes in human embryos has attracted most attention. Some argue that genome editing in human embryos should be pursued as it could prevent particular genetic diseases from being passed on from one generation to the next (Cavaliere 2018a; Gyngell et al. 2017). Others warn that it will be too difficult to (ever) assess the technology's safety, and that, therefore, we should probably not pursue it (Baylis 2017b; Lanphier et al. 2015). In addition, manipulating human genes more generally has been criticized on the ground that it will erode the intrinsic value of what is naturally produced (Kass 2004; Sandel 2004a), will be tantamount to 'playing God'<sup>177</sup>, or will result in the resurgence of eugenics<sup>178</sup>.

The debate on genome editing has so far primarily focused on ethical questions at the substantive ethical level, that is, questions about the moral status of genome editing and, especially, its application in human embryos. Limited attention has been devoted to questions regarding its regulation<sup>179</sup>. This limited attention is problematic, given the pressing need to regulate genome editing technologies, and the potential negative societal impact of regulations that alienate large swaths of society.

Since the debate on genome editing is just emerging, there is an opportunity to approach it with fresh eyes and to shape it in a way that includes discussions of ethical-political questions. In our view, such inclusion would ensure that regulations on genome editing take societal views into account, something which, as we will

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<sup>177</sup> For an analysis of 'playing God' arguments see for instance: Savulescu et al. (2009).

<sup>178</sup> Some have argued that gene editing could lead back to eugenics: see for instance: King (2017) and Pollack (2015).

<sup>179</sup> With some exceptions: see for instance: Baylis (2016, 2017b); Chan and Arellano (2016); Jasanoff et al (2015).



argue, is of the utmost importance if we want to implement ethically acceptable policies. Discussions of ethical-political questions regarding genome editing can also inform wider debates on the regulation of science in democratic societies characterised by a plurality of coexisting views. As Sheila Jasanoff et al. (2015) have pointed out, genome editing raises “basic questions about the rightful place of science in governing the future in democratic societies”, and as Françoise Baylis (2017b) has suggested, genome editing offers an opportunity to rethink existing mechanisms of public engagement and to identify the “common interests that might rightfully guide policy deliberations”.

We take on the challenges that Baylis (2017b) and Jasanoff et al. (2015) identify by exploring possible approaches to regulating genome editing that lie at the opposite ends of what we might call ‘the spectrum of public involvement in policy making’. We first sketch an approach that does not take into account the *actual* preferences of those potentially affected by genome editing and its regulation, but rather aims to derive at an abstract theoretical level what preferences people would have if they were committed to implementing public policies in a context of ethical pluralism; this is a strategy proposed by Joshua Greene. After pointing out a serious shortcoming of this approach, which we dub ‘elitist’, we present a diametrically opposed approach, as defended by Baylis and Jasanoff et al. We refer to this approach as ‘democratic’, as it emphasizes the importance of including the public’s expressed attitudes in the regulation of genome editing. We conclude that this approach also has a serious shortcoming and propose our own favoured approach, the ‘enlightened democracy approach’, which attempts to combine the strengths of the elitist and democratic approaches without their weaknesses. Our approach is inspired by the literature on deliberative democracy<sup>180</sup>. It relies on a democratic process as well as on expertise to identify people’s preferences and to develop policies that reflect them.

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<sup>180</sup> See for instance Gutmann and Thompson (1996); Cohen (2003); Gutmann and Thompson (2009); Kitcher (2001, 2011).

### 3.3 The Elitist Approach

Ideally, *since we live in democratic societies and we value democracy*, genome editing should be regulated in a way that all people *can* agree upon. However, universal or even very widespread agreement is unlikely to obtain, given that views at the level of substantive ethical questions tend to influence those at the level of ethical-political questions. Typically, those who think it is morally desirable, or even morally obligatory, to pursue genome editing will favour permissive regulations (Harris 2015; Savulescu et al. 2015), whereas those objecting to applications of the technology, or to the technology itself, will favour more restrictive regulations (Collins 2015; Lanphier et al. 2015; UNESCO IBC 2017).

How then are we to make progress at the level of ethical-political questions?

One approach we could adopt is to leave aside the expressed views on the regulation of genome editing and determine what people *would* agree upon *under ideal conditions*<sup>181</sup>. What these ideal conditions are is of course up for debate, but throughout history, many philosophers have focussed on the relevance of reason, or rationality, to the resolution of ethical questions.

For example, Baruch Spinoza wrote that:

[M]en who are governed by reason—that is, who seek what is useful to them in accordance with reason, desire for themselves nothing, which they do not also desire for the rest of mankind, and, consequently, are just, faithful, and honourable in their conduct. (Spinoza 1677/1996: XVII)

The idea is that people ‘governed by reason’ will agree upon universal norms that would apply to themselves as well as to others. Unfortunately, moral philosophers who have tried to ground their proposed ethical theories on the basis of reason alone have failed to reach an agreement on what reason requires or on what the rational – and therefore the ethical – way to regulate human behaviour is. Indeed, the two main normative ethical theories that both claim to be grounded in rationality –

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<sup>181</sup> Often, moral disagreement persists even in ideal conditions, among people that are well-informed and fully rational. This is what Doris and Plakias (2007) refer to as “fundamental disagreement”, which obtains even when ideal conditions are met.

Kantianism and utilitarianism – are often taken to lie at opposite ends of a spectrum, one grounding a strictly deontological approach and one grounding a strictly consequentialist one. How, then, could we rely on reason or rationality to determine how we should regulate genome editing? We could turn to political philosophers, but it seems like the best we can do then is to agree to disagree and to accept disagreement among reasonable ethical views within a framework of political liberalism (Rawls 1993). However, what liberal policies should admit as a reasonable view turns out to be difficult to establish, in particular when the disagreement is so deep that it involves not only substantive ethical views, but also ethical-political views. What kind of principles can reasonably settle a disagreement about how to regulate a technology whose moral status is the subject of substantive ethical disagreement? The answer remains unclear.

Perhaps we could turn to moral psychology for help. Recent work in moral psychology, particularly with regard to the interplay between reason and moral intuitions and emotions in our moral and political judgments (Greene 2014; Haidt 2012; Haidt & Björklund 2007), could potentially support ethical theories grounded in reason or rationality. In other words, an understanding of how moral judgments are formed could perhaps inform an account of how rationality could allow us to find some form of agreement at the ethical political level in the face of persisting and unresolvable disagreement at the substantive ethical level. In the remainder of this section, we focus primarily on how the work of Greene in moral psychology could underpin an approach that seeks to determine what regulations on genome editing people would agree upon if they were governed by reason. We do appreciate that Greene's work is debated on methodological and normative grounds (Kahane & Shackel 2010; Nagel 2013; Wright 2013) and we do not commit ourselves to his particular approach to the formation of moral judgments. What we are offering here is merely one possible heuristic that could underpin the 'elitist' approach, and what we say is compatible with rejecting some specifics of Greene's model.

On the basis of fMRI studies and psychological experiments involving people's responses to variations of the so-called trolley-problem (Foot 1967; Thompson 1976, 1985), Greene has developed a dual-process model of how people's moral judgments

are formed<sup>182</sup>. On Greene's model, there are two modes of making (moral) judgments: an automatic and a manual mode (what Daniel Kahneman would call "thinking fast" and "thinking slow"). In everyday situations, we normally make moral judgments in automatic mode, that is, on the basis of intuitive and emotive responses (such as the judgment that it is wrong to push a man onto the track so that he would stop a trolley and prevent five people from being killed). Such automatic mode is the result of how morality evolved to facilitate cooperation with other members of the small groups, or "tribes", within which individuals used to live. Responding to ethical dilemmas in automatic mode has resulted in different "tribes", or different moral communities, developing different intuitive and emotive responses (e.g. more conservative, or more liberal) to ethical dilemmas (Haidt 2012). This automatic mode coexists with the manual mode, which is guided by more reasoned reflections that can obtain once people set aside their intuitive and emotive responses.<sup>183</sup> According to Greene, the manual mode is what one could and should rely upon when it comes to solving moral conflicts arising between different moral communities. Such conflicts arise frequently today because of the globalized world in which we live, which often requires individuals belonging to different moral communities to find common solutions to ethical problems arising from the application and regulation of new technologies. Genome editing might well be one example.

Greene is convinced that if we could set aside our intuitive and automatic responses to the ethical questions that divide us, and reflect on these questions with the aid of our reflective cognitive capacities (the manual mode), we would be able to formulate a "meta-morality", that is, a "shared moral standard" (Greene 2014: 290) that is genuinely based on reason<sup>184</sup>. The meta-morality would be a "global moral

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<sup>182</sup> This is similar to the dual-process model that other psychologists developed with respect to the way humans make judgments more generally, see for instance: Kahneman (2011).

<sup>183</sup> The automatic mode is activated in trolley problem scenario in which we can save five people at the cost of killing one without having to actively push someone onto the tracks, something that many people intuitively reject.

<sup>184</sup> While the very same notion of "rationality" is itself difficult to define in philosophical terms, in psychological terms we can define practical rationality as the capacity to make decisions that are not based merely on unanalysed intuitions and emotions. In Greene's words, "Reasoning, as applied to

philosophy that can adjudicate among competing interests of its members” and that would allow to “make trade-offs among competing tribal values” (Greene 2014: 15). In order to make these trade-offs, however, we need a common currency of value that all human beings can acknowledge, even if it conflicts with some of the views developed in automatic mode (Greene 2014). Thus, even if some people disagree on the shared moral standard identified (due to their automatic moral mode), everyone should be able *to understand* (due to their manual moral mode)<sup>185</sup> this standard and its relevance for approaching ethical disputes. So, how to find this shared moral standard?

According to Greene, adopting the manual mode and favouring reasoned reflection instead of automatic intuitive responses to ethical questions allows us to appreciate that there are two essential aspects of a genuinely ethical approach. The first is the value of impartiality—the idea that, from the point of view of the universe (so to speak), each person is as important as any other. Greene acknowledges that none of us are really truly impartial, but notes that we can all acknowledge the importance of impartiality as a moral ideal (Greene 2014: 201). The second aspect of a genuinely ethical approach is the recognition of the value of happiness, which matters to everyone<sup>186</sup>. Recognizing that happiness is what ultimately matters and that, from the point of view of the universe, no one matters more than anyone else, lies at the core of utilitarianism, which Greene proposes to rename “deep pragmatism”. This is to emphasise that it is the approach that is most likely to work in resolving moral conflicts because it is the one on which people from different moral tribes could get to agree upon once they switch from the automatic to the manual mode of reasoning.

So, how could an approach based on Greene’s ideas about how to resolve moral disagreement in a globalised world help us regulate genome editing? Policies would need to be developed using the utilitarian standard. In other words, alternative

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decision making, involves the conscious application of decision rules (...). Reasoning frees us from the tyranny of our immediate impulses by allowing us to serve values that are not automatically activated by what's in front of us”, (Greene 2014: 13).

<sup>185</sup> Here is helpful Wright (2013) analogy of the meta-morality as “the moral equivalent of Esperanto”.

<sup>186</sup> This view that is shared for instance by Singer (1981) and Sidgwick (1907).

regulatory strategies would need to be evaluated on the basis of their capacity to generate the greatest happiness for the greatest number, as the famous utilitarian slogan goes. However, whether different types of policies to regulate genome editing can be expected to maximise happiness is a question that is not easily settled. Different sorts of experts, including for instance legal experts, policy-makers, scientists, ethicists, and sociologists could contribute to the assessment of the expected consequences of potential regulatory strategies, on what ‘happiness’ could mean, and on how the consequences could contribute to the promotion of happiness. Within this framework, a relevant and philosophically interesting question that would need to be addressed, but which we raise here only to leave it aside, is one about the proper role of ‘moral experts’<sup>187</sup>, i.e. people who know well different possible moral theories and know how to weigh conflicting moral values against one another in the light of those moral theories<sup>188</sup>. Presumably, these experts would be people who are able to switch to the manual mode and set aside automatically formed intuitions and emotions. Because the proposed approach heavily relies on some sorts of experts, we propose to refer to it as an ‘elitist approach’.

In principle, this approach could be the ethically optimal solution to the moral disagreement about how to regulate genome editing: it would be the solution that perfectly rational people would endorse. However, there are also some serious

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<sup>187</sup> There is a literature, both in philosophy and within bioethics specifically, about what moral expertise is, whether it exists at all, and who counts as a moral expert, with which we do not have the space to engage here. For the purposes of our paper, however, what matters is not so much how moral expertise should be defined and whether it exists, but the fact that the elitist model we discuss would have to rely on some sort of moral expertise – as well as on other kinds of expertise – rather than on the active participation of the population or of some representation of it.

<sup>188</sup> As Peter Singer says in his defence of moral expertise “[s]omeone familiar with moral concepts and with moral arguments, who has ample time to gather information and think about it, may reasonably be expected to reach a soundly based conclusion more often than someone who is unfamiliar with moral concepts and moral arguments and has little time” (Singer 1972: 117). Similarly, Harris and Lawrence (2018) argued that “‘Ethical expertise’ if and where it exists must consist principally in the ability to create, assemble, analyse or present the combination of evidence and argument required to establish, defend, qualify, weaken or demolish a proposition of ethical significance. Or, to reveal problems or ambiguities, contradictions or inconsistencies, in short strengths and weaknesses, in ethical positions, judgments, claims or conclusions”.

shortcomings with this view, which make it a problematic approach to regulating genome editing.

### 3.3.1 A Shortcoming of the Elitist Approach

We focus our criticism on an elitist approach modelled on Greene's proposal, but our arguments would also apply to other similarly elitist approaches.<sup>189</sup>

The most serious shortcoming is that the elitist approach is not democratic, in the sense that the decision-making process does not require the involvement and participation of all those who will be affected by the decisions taken. Why is this problematic?

Democratic decision-making procedures can be important for intrinsic reasons, for example because one values equality in political influence and sees democracy as the only system that can respect and preserve people's freedom, equality, and equality in freedom.

But a democratic decision-making procedure can also be important for instrumental reasons, because it is essential to achieve trust and legitimacy, which both have desirable consequences for society (House of Lords 2000). Relying on an elitist approach to regulate genome editing excludes large segments of the population from the decision making process. Expertise can often be "exclusionary and restricted" as it represents "the command of knowledge within a defined domain by some persons that is not commanded by others" (Archard 2011: 20). As a result, those excluded may lose trust in the policies resulting from the elitist approach and in the various experts that have contributed to them. Loss of trust in experts may have a wide societal impact. Moreover, when legitimacy<sup>190</sup> obtains, people are more inclined to conform to the policies and to avoid forgoing the potential benefits the technology

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<sup>189</sup> For instance, these arguments would apply to elitist approaches based on the alleged moral expertise of religious authorities.

<sup>190</sup> Here we follow Dryzek's (2001) definition of legitimacy, namely that "outcomes are legitimate to the extent that they receive reflective assent through participation in authentic deliberation by all those subject to the decision in question" (Dryzek 2001: 651).

in question may bring about. As is often highlighted in the literature on trust and expertise, it would be difficult for science to make progress without this trust (O'Neill 2002; Resnik 2011) and without legitimacy (Chan & Arellano 2016; Gutmann & Thompson 2009; Parkinson 2003). In addition, it has been argued that relying on a democratic process is good because involving rival points of view is more likely to lead to better policy outcomes, given that different ethical and practical problems are more likely to be considered and analysed<sup>191</sup>.

These reasons point to something similar: in liberal, democratic societies, public policies, and political decisions in general, cannot do without some form of support by the people who will be affected by those policies.

### 3.4 The Democratic Approach

This importance of relying on a democratic process to regulate genome editing echoes a shared view among the few scholars that have addressed the level of ethical-political questions specifically regarding genome editing (Baylis 2016, 2017b; Jasanoff et al. 2015; Jasanoff & Hurlbut 2018) (and indeed, some preliminary experiments of public dialogue in this direction have been carried out)<sup>192</sup>. It has been argued that an absolute condition of developing policies to regulate this technology is public engagement and the inclusion of public views in policy-making processes. Institutional bodies such as the US National Academy of Sciences (NAS) or the UK Nuffield Council on Bioethics endorse this view. For instance, following the December 2015 International Summit on genome editing, the NAS Organising Committee released a statement that called for the establishment of an “ongoing

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<sup>191</sup> This view was already defended by John Stuart Mill (1979/1859).

<sup>192</sup> The Royal Society – a U.K. learned society – commissioned both a public dialogue deliberative process (2013) and launched a survey (2017) on genetic technologies’ applications to plants, humans (heritable and non-heritable), non-human animals (pets, wild animals and animals used as source of food). A report of the survey and of the public dialogue is available at: <https://royalsociety.org/~media/policy/projects/gene-tech/genetic-technologies-public-dialogue-hvm-full-report.pdf> (last accessed April 25 2018).



international forum to discuss potential clinical uses of gene editing”. According to the statement, this forum should be “inclusive among nations” and should:

Engage a wide range of perspectives and expertise—including from biomedical scientists, social scientists, ethicists, health care providers, patients and their families, people with disabilities, policymakers, regulators, research funders, faith leaders, public interest advocates, industry representatives, and members of the general public. (National Academies of Sciences, Engineering and Medicine 2015)

Echoing this conclusion, Baylis (2016) emphasises the need to collectively discuss strategies for governance that are based on a “broad consensus” which, in turn, should be achieved through “broad-based participation by persons from around the world with a range of perspectives and interests” (Baylis 2016: 22).

An even more radical position is expressed by Jasanoff et al. (2015), who openly criticise the reliance on experts to address the regulatory challenges raised by genome editing and argue that public engagement cannot be reduced to asking questions to the public that have been pre-selected, pre-approved and deemed appropriate by experts. They claim that:

Even where there are calls for “broad public dialogue,” these are constrained by expert accounts of what is proper (and not proper) to talk about in ensuing deliberations. When larger questions arise, as they often do, dissent is dismissed as evidence that publics just do not get the science. [...] The impulse to dismiss public views as simply ill-informed is not only itself ill-informed but is problematic because it deprives society of the freedom to decide what forms of progress are culturally and morally acceptable. (Jasanoff et al. 2015)<sup>193</sup>

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<sup>193</sup> Elsewhere – and in a similar fashion – Jasanoff and Hurlbut have called for a “global observatory on gene editing” and argued that: “Free enquiry, the lifeblood of science, does not mean untrammelled freedom to do anything. Society’s unwritten contract with science guarantees scientific autonomy in exchange for a research enterprise that is in the service of, and calibrated to, society’s diverse conceptions of the good. As the dark histories of eugenics and abusive research on human subjects remind us, it is at our peril that we leave the human future to be adjudicated in biotechnology’s own ‘ecclesiastical courts’” (Jasanoff & Hurlbut 2018: 437).

### 3.4.1 A Shortcoming of the Democratic Approach

Unfortunately, the democratic solutions advocated by Baylis (2016, 2017b) and Jasanoff et al. (2015) also have a serious shortcoming. If one of the problems with the elitist approach was that it sacrificed democratic values for the sake of imposed rationally inferred moral values, the problem with the democratic model is rather the opposite one: it sacrifices reasoned and well-informed decision-making for the sake of democratic values. The problem with Baylis' (2016, 2017b) proposal is that due to the fundamental moral disagreement at the level of substantive ethical questions it is likely that a "broad based participation by persons from around the world with a range of perspectives and interests" will lead to fragmentation rather than to the widespread consensus that Baylis advocates. In addition to this, while it is true that Baylis does take into account certain conditions that need to be met in order to achieve her particular conception of consensus,<sup>194</sup> consensus may not be the most desirable aim to pursue, both because it may be a "mask hiding relations of domination and exclusion" (Callon et al. 2001: 4) and because it might be reached "to the detriment of opponents or the recalcitrant who have been unable to express themselves or who have been silenced" (Callon et al. 2001: 4)<sup>195</sup>. The problem with the proposal of Jasanoff et al. (2015) —we contend—is instead that it challenges the very idea of expertise and with it, the idea of relying on experts. This is problematic as many people's decisions may be uninformed or, if we may believe Greene, based on automatically formed and intuitive responses.

### 3.5 The Enlightened Democracy Approach

We propose that regulations for genome editing ought to be developed on the basis of what we call an 'enlightened democracy' approach, which, in our view, includes

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<sup>194</sup> Baylis (2016) does not really define what she means with consensus, but she is adamant in stressing that: "Consensus does not mean that everyone thinks that the decision made is necessarily the best one possible [...]. What it does mean is that in coming to that decision one felt that her position on the matter was misunderstood or that it wasn't given a proper hearing" (Baylis 2016: 22). The author also lays the condition of mutual engagement for achieve such consensus (responsibility, self-discipline, respect, cooperation, struggle).

<sup>195</sup> Callon et al. (2001) are quoting S. Jasanoff.

the strengths of the elitist approach and the democratic approach suggested by Baylis and Jasanoff et al., while avoiding to the greatest extent possible their shortcomings. The enlightened democracy approach to regulating genome editing relies partly on Greene's ideas of a shared moral standard and the relevance of experts in policymaking, and partly on the literature on deliberative democracy (Gutmann & Thompson 1996, 2009; Kitcher 2001, 2011). At the same time, our proposed approach takes up the challenges raised by Baylis and especially by Jasanoff et al. in favour of democratic deliberation and broad-based public engagement. Our proposal is enlightened in that it aims to include the various views of different categories of experts, and democratic in that it aims to open up the debate to various sorts of non-experts and engage with public views on genome editing.

The first characteristic of our approach is that it rejects an agenda for genome editing that is solely based on what experts define as worth pursuing. At the same time, it grants experts an ancillary but necessary role in the development of such an agenda. Building on the work of Philip Kitcher (2001, 2011), we argue that the policies regulating genome editing research and implementation should strive towards the ideal of "well-ordered science". According to Kitcher, scientific research and clinical applications are well-ordered when their agendas coincide with ideal deliberators' judgments and world views, which, in turn, are representative of the diversity of judgments and world views co-existing in a given community. In the context of genome editing and its applications, this ideal entails that such applications are well-ordered only if they align with what people—coming together and discussing their values and preferences—would decide in a deliberative process. The deliberations among people aim to provide "the most justifiable conception for dealing with moral disagreement in politics" (Gutmann & Thompson 2009: 10). This means that, as we saw above, even if disagreement often cannot be avoided, people's preferences should be taken into account in order to avoid distrust and illegitimacy. In addition, deliberations among peers facilitated and informed by experts allow that preferences are perfected and epistemic flaws ironed out. A deliberative process that involves both ordinary people as well as experts seems to us the most desirable strategy on two desiderata, namely:

[T]he degree to which policy outcomes match the substantive goals of society in question; and the degree to which they achieve normatively justifiable ends. (Parkinson 2003: 183)

The second characteristic of our proposed approach is that it sets certain background conditions to participating in these deliberations (Gutmann & Thompson 2009; Kitcher 2011). Contrary to the proposals such as those of Jasanoff et al. (2015) and, also, J. Benjamin Hurlbut, people entering these deliberations should meet certain criteria in order to avoid the two dangers outlined above (i.e. regulations that do not match societal goals and that do not achieve normatively justifiable ends). Deliberators need to meet “epistemic conditions” (Kitcher 2011) of mutual engagement, which require deliberators to not rely on false beliefs about the world, to be aware of the consequences of the debated matter for one another, and to know preferences and wishes of other deliberators. With respect to genome editing, this means that deliberators should gain a basic knowledge of the functioning, potential uses, potential risks and potential benefits of genome editing. Scientific experts, as well as social and technology studies experts, sociologists, philosophers, and lawyers would assist in bringing to light expected consequences of permissive or restrictive regulations for genome editing and make sure that deliberators can fulfil such epistemic conditions.

Other conditions for deliberators to take part in these discussions are ‘affective’ (Kitcher 2011), in that deliberators will be required to work towards the

[E]xpansion of one’s sympathies, in which the perceived desires of those with whom one deliberates are given equal weight with one’s own. (Kitcher 2011: 51)

These affective conditions of mutual engagement reflect also deliberative democracy’s background conditions of mutual respect (Gutmann & Thompson 2009). Only if both conditions apply is the process one of genuinely mutual engagement.

Moreover, epistemic and affective conditions allow for the emergence of and especially the discussion of “tutored” as opposed to “raw” preferences (Kitcher 2001, 2011). There is significant disagreement among experts about substantive ethical

questions regarding genome editing. These differences are likely to be equally found in wider society, where a plurality of values obtain (Haidt 2012; Nagel 1979, Ch 9). Hence, deliberators may have different preferences with respect to regulations and their judgments may be influenced by these preferences when they come together and discuss different possible routes for scientific research and applications. The preferences that these individuals discuss should however not be “raw” preferences influenced by whatever inclination or temporary impulse these individuals are subjected to; in other words, the preferences should not be devoid of any background information, but rather “tutored preferences”: preferences informed by the current state of the art of the matter, and especially by the significance that potential applications of the technology in question may have for people’s lives (Kitcher 2001: 118). In addition to this, these preferences should be tutored in the sense that they will be perfected in a discussion with experts and in a discussion with epistemic peers (e.g. other members of the public participating in the deliberative processes).

In our view, these characteristics enable a deliberative process to take place, one that avoids what in our view are the most problematic shortcomings of the elitist and democratic approach to regulating genome editing. The enlightened democracy approach could be criticised on practical and ethical grounds too, but we contend that its shortcomings should be factored against the benefits and the shortcomings of the alternatives thus far proposed. From a practical point of view, our proposed approach may still generate or fail to solve disagreement. Disagreement at the first level (the substantive-ethical) and disagreement at the second level (the ethical-political) are interlinked and mutually influenced. However, even if there is lingering disagreement, our approach will reduce the risk of stifling policy-making processes, as at least epistemic flaws will have been mitigated and the different moral beliefs and preferences discussed. As argued by Philip Kitcher (2001, 2011), Amy Gutmann and Dennis Thompson (1996, 2009), Joshua Cohen (2003) and—from a different perspective— Jonathan Haidt (2012), the give-and-take of preferences and judgments allows for addressing misapprehensions and for appreciating the value of moral beliefs different from our own. In the best-case scenario, recognising the value of other points of view will help deliberators to engage with these points of view and

perhaps to reflect on their own moral beliefs. This could help the activation of Greene's manual mode and allow for a reasoned reflection to emerge. In some cases, the disagreement will not be resolved, and the debate will remain polarised, but the mutual engagement would hopefully mitigate legitimacy problems and distrust. Our proposed approach will be criticised by those who would grant more "power to the people" and those who are wary of any involvement of experts as they pre-determine the questions that are worth pursuing and hence limit the scope and type of questions that are discussed in these deliberations (Hurlbut 2017). It will be also criticised by those who are wary of involving the public in discussions concerning new technologies and how they should be regulated. Without entering into a complicated discussion with both sides on burden of proof, we contend that our approach accommodates these competing views better than the alternatives.

### 3.6 Conclusion

In this paper, we have proposed an approach to addressing ethical-political questions regarding genome editing—i.e. questions about how genome editing should be regulated in the face of deep and persistent disagreement about substantive ethical questions. We have sketched a possible elitist approach grounded in the meta-morality proposal of Greene and based on the deliberation of some sort of experts, and then discussed the democratic approach proposed by Baylis and Jasanoff et al. We have argued that the approaches each have their strengths, but also significant shortcomings. We have then proposed a new approach—the "enlightened democracy" approach—that aims to reconcile the need for a democratic engagement involving mutual respect for competing views on the one hand, and a well-informed discussion on the other. Our proposal is meant to sketch a theoretical framework to inform the ethical debate on how to regulate genome editing. We appreciate that our proposed approach would need to be further developed and refined. Most notably, we have not addressed the question of how such an approach would translate into practice. In this sense, our paper is situated within the scholarship in moral and political philosophy that proposes approaches to regulate new technologies in pluralistic and democratic societies. We believe however that a

study of the implementation of the enlightened democracy approach would be worth pursuing, perhaps in another paper.

### **3.7 Acknowledgments**

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#### 4 Conclusions to Part III: Compromise and Democratic Engagement

In the two papers incorporated into Part III of this thesis, I discuss the possibility of extending the statutory limit for embryo research and the possibility of allowing genome editing applications to early human embryos. While both possibilities are a matter of debate and have given rise to substantial moral disagreement, certain conditions need to be met prior to going forward. As others argue (see for instance Devolder 2017; Montgomery 2017), with respect to embryo research, any case for extending the limit would have to show on the one hand that “significant scientific gains can reasonably be expected” (Montgomery 2017: 7) from such an extension. On the other hand, it would need to show that the proposed change would set “a new regulatory constraint that could play the jurisdictional role” (Montgomery 2017: 8) identified by the current limit. With respect to genome editing, scientists who are currently conducting basic research with human embryos and scientists applying to conduct further research (and clinical research) would have to show that the current drawbacks of the applications can be overcome, and that the technology is safe enough to move to clinical research. While all these are necessary conditions to move forward, in my view they are not sufficient to this end. Scientific gains and safety should not be the only standards against which the decision to allow new reproductive technologies are measured. Public involvement and deliberations on the public value of these technologies, of how they can be implemented in ways that fairly distribute their burdens and benefits among people directly and indirectly involved, and of the “biological futures people actually want for themselves and their societies” (Jasanoff & Hurlbut 2018: 436) need to be part of the ethical debate too. It is for this reason that in both papers I discuss what my co-authors and I refer to as ethical-political questions at the second level (Cavaliere et al. 2019).

In Paper 5 (Cavaliere 2017), I argue that the Warnock approach of favouring a solution of compromise<sup>196</sup> between competing ethical views was the best way to

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<sup>196</sup> Devolder (2017) argues that the 14-day limit, albeit “defended as a compromise between scientists who wanted to conduct embryo research (or whose work could benefit from such research) and those opposing all embryo research” (Devolder 2017: 78), was not really a compromise, as to be classified



respect the plurality of values which underpinned these competing views. In Paper 6 (Cavaliere et al. 2019), I outline an approach to regulate genome editing that seeks to promote public involvement in deliberations while at the same time placing some conditions on the involvement process.

Following Archard (2012), compromise is:

[T]he making of mutual concessions by two or more parties who disagree in respect of some matter. An agreed outcome can only be secured if each is prepared to settle upon something that is for each party inferior to what was originally sought. (Archard 2012: 403)

According to this definition, moral compromise is hence an “agreement in the face of moral disagreement”, which can secure a “morally desirable outcome” on an “ethically contentious issue” (Archard 2012: 404). In Paper 5, I argue that compromise can best respect the plurality of values and ethical views on embryo research and that a truly democratic approach would have to take these values and views into consideration<sup>197</sup>. Similarly, a democratic approach would take values, ethical views, and preferences (Cavaliere et al. 2019) into account, but it would set

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as such both sides would have had to make concessions. According to the author, however, the 14-day limit “*gave scientists virtually everything they needed at the time*” ([emphasis added] Devolder 2017: 78). While I understand Devolder’s reasoning, and I think she is right in saying that all that scientists (and proponents of embryo research) needed at that point in time was a limit that would allow them to conduct research (and it was not technically possible to sustain embryos in vitro for more than seven to nine days), my view is that, at that point in time, it was indeed a compromise. The compromise happened between those who wanted to have no line in the sand and to model regulations on technical capacity (present and especially future) and those opposing embryo research. The decision to set the limit at 14 days was more agreeable to the former than to the latter group, but it was an instance of compromise as both sides had to make concessions on their original positions. As Archard (2012) argues: “In any compromise one party can get more out of the deal relative to the claim originally advanced than the other manages relative to her initial claim” (Archard 2012: 403). Chan (2018) too refers to the decision to set the limit at 14 days as “a sort of policy compromise” between “groups with radically different interests and views on the moral legitimacy of embryo research” (Chan 2018: 229).

<sup>197</sup> This is also a view discussed and defended by Bellamy and Hollis (1998): “In principle, compromise shows a laudable willingness to see another’s point of view, thereby showing a decent respect for pluralism. The spirit is more than one of tolerance in the weak sense of putting up with people one disagrees with” (Bellamy & Hollis 1998: 54). Contrary to Bellamy and Hollis (1998) and the view that I defend in Paper 5, critics of liberal theorists and of the tradition of political liberalism such as Chantal Mouffe (2000, 2013) argue instead that to be truly democratic, political systems need to embrace an antagonist’s perspective. This perspective does not seek to negotiate a compromise between competing views and interests nor seek to overcome opposition. Rather, it is a perspective that embraces this opposition and seeks to negotiate within democratic objectives.

some conditions for the process – which I explore in Paper 6. Both compromise and our proposed ‘enlightened democracy’ approach are open to criticism. As, for instance, Archard (2012); Richard Bellamy and Martin Hollis (1998); and Devolder and Douglas (2018) note, compromise is often frowned upon and considered problematic<sup>198</sup>. The reasons for this are manifold and include, for instance: compromises’ lack of sound theoretical foundations (as the debate on the 14-day limit exemplifies); their “shrinking deference for the *status quo*” (Morely 1901: 19); the lack of integrity of the compromisers (as Bellamy and Hollis [1998] put it: “to compromise is to compromise oneself” [Bellamy & Hollis 1998: 55]); or even their becoming complicit in wrongdoing<sup>199</sup>; and the epistemic cost<sup>200</sup> that defending a compromise can have (Devolder & Douglas 2018). Similarly, a democratic approach that takes into account people’s preferences can be criticised by those who worry about the higher potential for cognitive errors and wrongful moral convictions of the public (as opposed to, for instance, scientific and ‘moral’ experts), and by those, such as Jasanoff et al. (2015) and Jasanoff and Hurlbut (2018), advocating for reducing constraints on participations in democratic deliberation. More fundamentally, as Hurlbut (2017) argues with respect to the debate on embryo research in the U.S., such a democratic approach would be criticised by those who are dissatisfied with the standards of rationality and ‘public reason’ that a framework inspired by political liberalism draws upon.

In the two papers incorporated into this part of the thesis, I have provided instrumental and intrinsic reasons to adopt a solution of compromise within the debate on extending the 14-day limit. I have also provided reasons to adopt a democratic approach informed by the deliberative democracy framework (Bohman

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<sup>198</sup> Authors have been ambivalent on compromise too (for a discussion, see for instance Archard 2012; Braybrooke 1982; Nachi 2004).

<sup>199</sup> For a discussion of these positions, see Devolder (2015); Devolder and Douglas (2018); Bellamy and Hollis (1998).

<sup>200</sup> Douglas and Devolder (2018) argue that the view that compromise is almost always problematic (what they refer to as “the common sense view”) cannot be defended using the currently available reasons to hold this view, as such reasons apply only to some compromises. By contrast, they argue that the common sense view can be vindicated following an “epistemic cost account”. According to this account, compromise can be problematic because it can “impede the future formation of correct ethical beliefs” (Devolder & Douglas 2018: 115).

1998; Elster 1998; Gutmann & Thompson 1996, 2009) and by the well-ordered science framework (Kitcher 2001, 2007, 2011) within the debate on genome editing applications to human embryos. Granted, these solutions and approaches are open to criticism on philosophical, epistemic, moral, and practical grounds. They may require a pre-emptive commitment to democratic governance that philosophers would rightly criticise as a cheap and fallacious argumentative strategy (as this argumentative strategy would need to presuppose too much). Despite this, the ethical questions on new reproductive technologies that are the object of this part of the thesis are not solely theoretical-ethical questions but political-ethical questions with implications for debates on public policy. As Bellamy and Hollis (1998) argue:

[L]iberals have principled as well as pragmatic reasons for embracing compromise. It goes together with a democratic politics informed by duties of mutual respect and a concern with the common good, in which the only people who are compromised are those who through prejudice or selective blindness refuse to compromise at all. (Bellamy & Hollis 1998: 76)

In this sense, albeit far from being perfect, the approaches I have defended are in my view the best of all possible worlds, considering the costs of following alternative approaches within debates concerning the public policy arena.

# PART IV

## Back to Eugenics: Procreation beyond the Procreators' Interests

### 1 Introduction to Part IV

In this final part of the thesis, I intend to (partially) move away from discussing the ethics of new reproductive technologies to focus on procreative decisions and procreation more broadly. As I have explained in the introduction to this thesis, within this project I employ the term procreation to refer to activities which result in bringing children into existence and to capture some of the broader, cumulative and far-reaching effects of these activities. My discussion takes as a point of departure reproductive freedom (Buchanan et al. 2001, Ch 6) and seeks to question the individual-centred ethical framework that underpins this principle. To do so, I analyse strengths and weaknesses of this individual-centred framework and those of (past and contemporary) alternative frameworks to address ethical challenges raised by procreative decisions. I also bring together critiques to this framework from strange bedfellows such as economists, philosophers, environmentalists and critical social scientists. The object of Part IV is hence to discuss questions pertaining to people's interests in procreative matters (broadening the analysis of the preference for genetic relatedness that is the object of Part II) and an evaluation of whether there can be ethically acceptable limits to the satisfaction of these interests.

Turning back to the aims of this project outlined in the introduction, this part of the thesis juxtaposes the methodology-oriented and the content-oriented aims. Firstly, it seeks to change the way authors participating in debates on the ethics of procreation reflect on procreative decisions and to include observations on the implications of such decisions. This is achieved by including other relevant insights pertaining to the cumulative and far-reaching effects of procreation and by drawing on a multiplicity of disciplinary sources. Secondly, it seeks to examine and assess

different strategies to address ethical challenges raised by procreative decisions which can fairly distribute the burdens and benefits of such decisions.

In the introduction to this thesis, I have argued that debates on the ethics of new reproductive technologies and on the ethics of procreative decisions more generally should be interpreted as debates about who should come into existence and about how to balance the burdens and benefits of such decisions. As I showed in Paper 1 (Cavaliere 2018d), the relationship between new reproductive technologies and 20<sup>th</sup> century eugenics is fraught with controversy. Several authors hold that these technologies do not resemble eugenics in meaningful ways and that a comparison of the two is not warranted<sup>201</sup>. Many of these authors rely on the distinction between individual-level and population-level interventions to “draw a bright line” (Buchanan et al. 2001: 53) between “eugenics as an intervention *on behalf of public health and welfare*, and clinical genetics, *in service of the individual*” ([emphasis added] Buchanan et al. 2001: 53). However, the distinction between individual-level interventions as the defining characteristic of new reproductive technologies and population-level interventions as the defining characteristic of eugenics has been challenged. Both 20<sup>th</sup> century eugenics and new reproductive technologies feature aspects that pertain, in different ways and degrees, to both levels (Bashford 2010; Buchanan et al. 2001; Löwy 2015). Despite these challenges, population-level interventions in procreation are still deemed more ethically troubling than individual-level interventions. I would argue that this happens on the one hand due to the perceived risk of violating people’s reproductive freedom; on the other, due to the perceived risk of causing harms and wrongdoings akin to those that occurred as a result of 20<sup>th</sup> century eugenics’ policies, ideologies and practices.

In this final part of my thesis, I hence turn back to eugenics in more significant ways than in the rest of my work. I discuss whether it is possible to move from an individual-centred framework to reflect on the ethics of procreative decisions, to a

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<sup>201</sup> See Paper 1 (Cavaliere 2018dCavaliere 2018d).

framework that considers other people's (than the procreators') interests, and the far-reaching and cumulative effects of individual procreative decisions.

### **1.1 Reproductive Freedom and the Individual-Centred Framework**

Reproductive freedom plays a pivotal role in debates on the ethics of new reproductive technologies. It protects people's interests in procreative matters and allows them discretion in the matter of whether or not to have children, the number of children they have and, to a certain extent, in countries that allow assisted reproductive technologies, on the type of children they have (Buchanan et al. 2001, Ch 6; Brock 2005; Dworkin 1993; Harris 1998; Robertson 1994). It is perhaps unsurprising then that reproductive freedom is invoked to defend these technologies and to criticise restrictions to access them, such as statutory bans and other kinds of interferences on the part of the state. For instance, as I showed in Paper 3 (Cavaliere 2018a) and in Paper 4 (Cavaliere & Palacios-González 2018), within debates on MRTs and on genome editing people's freedom in reproductive matters is a powerful and pervasive argument to justify the introduction of these and other technologies. Similarly, a concern for people's reproductive freedom often grounds authors' defences of pre-natal and pre-implantation technologies, the right to terminate an unwanted pregnancy, and access to contraception and reproductive care. This principle sits at the core of these defences due to the relevance of exercising freedom in reproductive matters for people's autonomy and well-being. In turn, limiting reproductive freedom is considered problematic insofar as it could negatively affect people's personal autonomy and well-being. For instance, Brock (2005) argues that personal autonomy serves as the primary moral basis of this principle. In his words:

Individuals' interest in autonomy is their interest in making significant decisions about their lives for themselves and according to their own values or conception of a good life, carrying out those choices without interference from others, and being free to revise their plans of life or conception of the good over time. [...] Because the choice of whether to reproduce has such far-reaching impact on people's lives, their autonomy interest in making it is typically great. (Brock 2005: 382)

The other “principal moral basis” (Brock 2005: 383) of reproductive freedom, according to Brock (2005) and others (Buchanan et al. 2001, Ch 6; Robertson 1994), is people’s well-being. Following this view, having and raising children<sup>202</sup> are core human activities which are “central to personal identity, to dignity, and to the meaning of one’s life” (Robertson 1994: 24). The recognition of and concern for people’s autonomy and well-being count among the theoretical successes of reproductive freedom. Not only that, as I have argued in Cavaliere & Harris (2018)<sup>203</sup>, reproductive freedom plays and has played an important performative role in contemporary and past political struggles to secure access to contraception, terminations of pregnancies, and to allow new reproductive and screening technologies (see also: Mills 2015). On both accounts, then, reproductive freedom seems to have a positive track record in terms of theoretical and practical successes in protecting people’s interests. Moreover, as I have discussed in Paper 1 (Cavaliere 2018d), the history of 20<sup>th</sup> century eugenics serves as a reminder of how procreation was thought to be a matter of concern for the state<sup>204</sup>, which could legitimately exercise control over the bodies of women, ethnic minorities, disabled and poor people, and other vulnerable groups (see also Connelly 2008).

## 2 Challenges to Reproductive Freedom

By and large, reproductive freedom’s theoretical and political emphasis on people’s autonomy, dignity and well-being fits within an individual-centred framework to discuss the ethics of procreation. It protects people’s interests from external interference and it prevents (or, at least, it significantly reduces) the ethically and legally permissible grounds for interference by third parties. It is in this sense that, within the framework of reproductive freedom, procreation is often both thought to be a private matter and is defended for this reason. As with other freedoms protected

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<sup>202</sup> As well as not having children: reproductive freedom also protects people’s interest in not having children, and it is often defended as a right to self-determination and bodily autonomy in debates on the ethics of abortion (Cavaliere & Harris 2018) and contraception (Ceva & Moratti 2013).

<sup>203</sup> This paper is not incorporated into this thesis. See footnote 148 in Part II.

<sup>204</sup> See also Michel Foucault (1978) on this issue.

in liberal democratic societies, the freedom to decide in matters of procreation is not absolute and other considerations can rightfully constrain its scope (Brock 2005; Dworkin 1993; Cavaliere & Harris 2018). Such considerations often pertain to limits to reproductive freedom put in place to protect the well-being and the interests of the child who is born as a result of the procreative act. For instance, reproductive freedom protects people from interference in the choice of whether to become pregnant and whether to continue a pregnancy, but it would not protect them from interference against consuming harmful substances during pregnancy. Consuming substances may harm the (future) child<sup>205</sup> and hence constitute a legitimate reason for third-party interference (for a critical analysis of the concept of the welfare of the child within decisions about assisted conception, see Parker 2005a). More controversial, within the reproductive freedom framework, are interferences motivated by a concern for the well-being of others, for their interests and/or by the risk of harm occurring to others. The received view on reproductive freedom broadly entails that third parties' interests are less morally significant than the interests of the procreators, and that these interests often do not amount to justifiable grounds for interference (Harris 1998; Mills 2013; Robertson 1994). Other than the exception of the child's welfare, defenders of reproductive freedom consider few grounds for interference ethically justified; curtailing or limiting reproductive freedom is often resisted due to the negative impact on people's well-being and autonomy.

In the next two sections, I present and discuss critiques of reproductive freedom which are motivated by a concern for the well-being of others, for their interests, and/or by the risk of harm occurring to others<sup>206</sup>. These critiques and the challenges

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<sup>205</sup> Parfit (1984) showed that discussions on placing moral obligations on present persons to refrain from harming future persons generates what he defines as the non-identity problem. This problem arises as present decisions about future people (such as the timing of conception or whether to use a technology for assisted reproduction) are identity-affecting, namely they determine who will be born. Consequently, discussions on the welfare of the future child are complicated as it is metaphysically problematic to place moral obligations on individuals regarding future people. The point here is not whether we can place moral obligations on prospective parents but that in debates on procreation, concerns for the welfare of the child are considered one of the most important constraints to the scope of reproductive freedom and are used as an argument to legitimately limit such freedom.

<sup>206</sup> Some of the critiques of the individual-centred framework and to reproductive freedom are motivated by a broader critique of the dominant individualistic understanding of the principle of



they raise for the individual-centred framework vary greatly in terms of the ethical concerns that they voice and in terms of the proposals advanced to address such concerns. In my view, what unites them is that they can all be interpreted in terms of pointing to the inadequacy of an ethical framework that solely focuses on the interests of individual procreators and their close networks. My focus is on two sets of challenges to reproductive freedom and its non-interference clause:

- 1) challenges motivated by the potential and actual harms that already discriminated-against groups such as ethnic minorities, women and disabled people may suffer
- 2) challenges motivated by a concern for the size and the structure of the population, and by how procreation negatively affects third parties due to increased size or to sub-optimal structure.

I elaborate on each of these sets of challenges in the following sections.

### **2.1 First Set of Challenges: Engendering Harm to Vulnerable Groups**

The first set of challenges concerns potential and actual negative effects engendered to ethnic minorities, women and disabled people. For instance, Roberts (1997) criticises defences of reproductive freedom for their focus on abortion rights and promoting access to assisted reproductive technologies. She argues that, while

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autonomy within healthcare settings (for a review and a discussion of an alternative proposal, see Dove et al. 2017) and the excessive emphasis on this principle in that context (Thomasma 1983). Other critiques take issue with an approach – within discussions on reproductive rights and reproductive health – that focuses mostly or solely on removing barriers of access to reproductive services and care, and on non-interference clauses which protect citizens from the interference of the state in reproductive matters (Mills 2013; Roberts 1997). Relatedly, some authors have criticised the language of ‘choice’ and how it masks the constraints women experience in real-life situations (Lippman 1999; Löwy 2015; Roberts 1997; Rothman 1985; Samerski 2009). According to these authors, this focus on choice and on non-interference leaves structural injustices and other legal, economic, social and political barriers to accessing reproductive services and care untouched (Löwy 2015; Roberts 1997); it favours commercial rather than women’s interests (Rothman 1985; Samerski 2009) and it renders hegemonic certain norms and ways of conduct, thereby constraining women’s freedom (Mills 2015). I return to some of these critiques in the next section, where I limit my analysis to critiques to reproductive freedom and to the individual-centred framework which are motivated by a concern for the interests and the well-being of others (i.e. other than the procreators and their close networks).

protecting the interests of some (wealthy, educated, white people), these narratives often both overlook the rights of ethnic minorities and indirectly harm them:

Liberty only commands that the government stay out of people's decisions, which individuals are free to make as long as they do not cause *tangible* harm. This means that the government need not to be concerned with social practices that create such vague injuries as the devaluation of Black mothers. ([emphasis in original] Roberts 1997: 295)

Something similar, in terms of the harm engendered to third parties, is discussed within debates on pre-natal screening and on selecting against disability. Many authors (including myself) defend the right of women and couples to access pre-natal and pre-implantation testing technologies to make more informed decisions regarding the type of children they will bring into existence and raise (see for instance Harris 1998; Shakespeare 2006). This right is protected by reproductive freedom as it allows women and couples to make decisions which are in line with their preferred life-plans. People undertaking prenatal and pre-implantation tests can subsequently decide to 'select out' foetuses or embryos which may grow into disabled children. Disability scholars criticise these technologies for different reasons. Some see them as a morally problematic means to achieve otherwise good ends as they entail selection "in the name of disability prevention" (Asch & Barlevy 2012: 1). Others see them as morally problematic because the decision to abort a foetus with chromosomal abnormalities, such as those linked to Down's syndrome, is often made without an accurate and embodied idea of what it means to live with a disability (Mackenzie & Scully 2007). Some, crucially, see these options as responding to a "eugenic logic" (Garland-Thompson 2012: 339) which is part of:

[O]ur dominant understanding that disability is something to be avoided and that the world would be a better place if disability would be eliminated. (Garland-Thompson 2012: 339)

According to Rosemarie Garland-Thompson (2012) this logic is problematic as it portrays disability in negative terms while, she contends, disability should be considered a resource worthy of conservation<sup>207</sup>.

Reproductive freedom is not responsible for engendering harms to ethnic minorities (Roberts 1997), disabled people (Garland-Thompson 2012) or women (Shahvisi 2018; Smith 2005). Despite this, according to authors voicing the concerns just outlined, it protects the interests of certain people (the procreators) while failing to take other interests into account and to limit potential and actual harms to third parties. Moreover, as argued by Roberts (1997) and by proponents of the reproductive justice movement<sup>208</sup> (Price 2010; Ross 2005, 2006; see also: Mamo & Alston-Stepnitz 2015), the reproductive freedom framework protects the interests of the well-off by removing legal barriers (and by limiting the interference of the state) to access to reproductive technologies, contraception and abortion services. It allows, in other words, those with financial means and who belong to certain social and cultural groups to freely decide in procreative matters by removing the only barrier between them and the possibility of exercising their freedom<sup>209</sup>. Reproductive freedom, especially when conceived in terms of ‘freedom from’ interference or ‘negative freedom’ (Mills 2013), protects against third parties’ intrusion in procreation. But, as Roberts (1997) argues:

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<sup>207</sup> A similar point is made by Gyngell and Douglas (2016), and by Jonathan Anomaly et al. (2018), but it is limited to cognitive diversity and, in particular, to dyslexia and Asperger syndrome.

<sup>208</sup> Reproductive justice is a U.S. concept that seeks to bring together the demands of reproductive rights activists and of social justice frameworks (Mamo & Alston-Stepnitz 2015). The driving force behind this project is to shift from a rhetoric of ‘choice’, a focus on negative rights and access to abortion to a rhetoric focusing on the political, economic and social inequalities which constrain women’s procreative activities and rights. According to proponents of this framework, such as Loretta Ross (2005, 2006; see also: Asian Communities for Reproductive Justice 2005), reproductive justice seeks to address structural inequalities which affect women’s lives and reproductive health, rather than merely channelling efforts towards removing legal barriers to accessing services.

<sup>209</sup> According to the proponents of the concept of ‘stratified reproduction’ (Colen 1995) outlined in the introduction, this analysis misses the fundamental role of power relationships and of power asymmetries within these discourses (see also: Ginsburg & Rapp 1995).

[I]t does nothing to dismantle social arrangements that make it impossible for some people to make a choice in the first place. Liberty guards against government intrusion; it does not guarantee social justice. (Roberts 1997)

The impossibility to enjoy freedom in matters of procreation due to financial, cultural and social barriers, as well as due to existing racist, sexist and ableist forms of discrimination is one of the challenges raised against the individual-centred framework of reproductive freedom. The critiques outlined in this section can be interpreted in terms of challenges to a framework that protects certain interests (those of the procreators, and specifically – following the authors discussed in this section – of the well-off, white and able procreators) while overlooking the effects on third parties of protecting these interests. In other words, what reproductive freedom and the individual-centred framework that underpins it overlook are the cumulative and far-reaching effects of procreative decisions.

### **2.2 Second Set of Challenges: Population Engineering**

Another set of challenges to reproductive freedom and to the individual-centred framework that underpins it comes from the increasing number of authors who in the past few years have begun to advocate for some kind of ‘population engineering’. Population engineering, following Colin Hickey et al. (2016), refers to “the intentional manipulation of the size and structure of human populations”<sup>210</sup> (Hickey et al. 2016: 845). The claims of authors advocating for population engineering differ in terms of the policy solutions advocated, the degree of coercion that they find acceptable, the aims that drive them, and in terms of placing the emphasis on the size of the population and/or on its structure. Primarily, they make two types of claims: Malthusian-inspired claims regarding the size of the population (Benjamin et al. 2017; Cafaro 2012; Das Gupta 2014; Hickey et al. 2016; Rieder 2015b, 2016;

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<sup>210</sup> Throughout this final part of the thesis I refer to these categories, i.e. size and structure, as I follow Colin Hickey et al. (2016)’s definition of population engineering. While what they mean by population ‘size’ strikes me as intuitive, when I discuss population ‘structure’ I am referring to composition: namely to the type of people who collectively shape the population.

Young 2001) and eugenics-inspired claims<sup>211</sup> regarding the structure of the population (Anomaly 2014, 2018; Brock 2005). The first group of authors focuses on the toll on resources and on the environment of bringing new persons into the world. They maintain that there are good moral reasons to favour adoption instead of relying on costly assisted reproductive technologies (Overall 2012; Rulli 2014), to refrain from having more than one child (Rieder 2016), to pursue alternative ways to ‘make kin’ instead of procreating (Haraway 2015) and to forgo or limit procreative aspirations altogether (Cafaro 2012; Das Gupta 2014; Rieder 2016; Young 2001). The second group focuses instead on population structure and on the costs of unconstrained procreation for current and future generations. Their view is that the problem with an unconstrained procreative behaviour is not ‘too many people’, but too many *of a certain kind* of people (Anomaly 2014, 2018; Anomaly & Boutwell 2017; Brock 2005).

What unites the claims of authors concerned with the size of the population and authors concerned with its structure is that they challenge reproductive freedom and the individual-centred framework that underpins it by proposing a framework that pays attention to the collective effects of individual procreative decisions. These authors also broadly agree that the interests of existing and future people may constitute a *pro tanto* reason in favour of interfering with prospective parents’ reproductive freedom<sup>212</sup> (Anomaly 2014, 2018; Brock 2005; Rieder 2016; Rulli 2016b). In the next sections, I present and discuss their proposals for population engineering. I do so by evaluating the strengths and the weaknesses of the broader

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<sup>211</sup> I am aware that Malthusianism can be understood in terms of eugenics (following the understanding of eugenics that I rely upon within this thesis) and that the two phenomena are often not clearly distinguishable. In this final part of the thesis I use both terms as Malthusianism historically placed a stronger emphasis on population size, eugenics on population structure. There were overlaps historically and there are overlaps within the claims of the authors I discuss in this part of the thesis. As I argue towards the end of this final part of the thesis, population engineering programmes concerned with the size of the population will have to address issues concerning its structure too and vice versa.

<sup>212</sup> As mentioned above, the challenges to and critiques of reproductive freedom and the individual-centred framework that underpins it of these two groups and the challenges and critiques from the point of view of disabled people, women of colour and other authors presented in the previous section are different in terms of the ethical concerns voiced and in terms of the proposals to address these concerns. Despite this, they can both be considered as pleas and arguments to reflect on the ethics of procreation from a broader perspective than that of the reproductive freedom framework.

framework that they employ: one that considers the interests of other people than the procreators and their close networks.

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Two conclusions can be drawn from the two sets of challenges just discussed. Firstly, the individual-centred framework to reflect on the ethics of procreative decisions does not account for other people's ethically significant interests and for the effects of procreative decisions on these people (and their interests). Secondly, the current framework protects only *certain* individual interests and not those of all engaging in procreation (even within liberal democratic societies which respect and protect reproductive freedom). Looking at the effects of individual procreative decisions on vulnerable groups, on the environment, and on political and social institutions allows us to appreciate many more elements than the individual-centred framework of reproductive freedom can account for and to make trade-offs in terms of what considerations should be given priority. The question, then, is: are alternative frameworks to discuss the ethics of procreation theoretically and practically better than the individual-centred framework of reproductive freedom? In the following section, I outline some of the proposals that have been put forward to reflect on the ethics of procreation more broadly.

### **3 Procreation and the Broader Framework**

Decisions of whether to procreate or not, with whom and how are protected by reproductive freedom, but, at the same time, inevitably affect the size and the structure of the population. They have effects on the third parties whose interference reproductive freedom protects against. That these decisions affect the size of the population seems relatively uncontroversial: some of us have siblings and some of us do not due to the procreative decisions of our parents. More generally: the decline in fertility rates of people living in developed countries and, to a lesser extent, in developing countries, affects the number of people who will inhabit our planet in the future, and this trend depends on the cumulative effects of the procreative decisions of people currently living in these countries.

Procreation can also affect the structure of the population. The Zika virus epidemic that began in early 2015 in Latin America offers an example of this. Procreating during the epidemic meant that children had a higher risk of being born with physical abnormalities than, say, before or after the epidemic. Something similar can be said about hereditary conditions such as mtDNA diseases. Procreating ‘naturally’, i.e. without turning to IVF coupled with PGD or to MRTs, means that children born as a result of the procreative act will have a higher than normal chance of having mtDNA mutations which could lead to the onset of mtDNA diseases. In turn, relying on MRTs, PGD or seeking an oocyte donor decreases the risk of having a child with mtDNA mutations which could lead to mtDNA diseases.

Naturally and humanly constituted environments of a certain geographical region play a role in shaping people’s procreative decisions and, consequently, influence the size and the structure of the population. For instance, living in a region affected by extreme climatic conditions or by violent conflict (say Syria between 2010 and 2018), as opposed to living in a region with favourable climatic conditions and functioning institutions (say the Silicon Valley during the same period of time) can play a role in people’s decision to procreate or not (and of how many children to have) thereby changing the size of the population. These conditions however can also influence the structure of the population insofar as if people have children in the Silicon Valley instead of in Syria, the future children of these people may have access to different nutrients, grow up in an environment where different resources and institutions are available thereby changing the structure of the population (on this issue, see also: Del Savio et al. 2018)<sup>213</sup>. More controversially, but also importantly, these humanly and naturally constituted environments do not only play a role in shaping people’s procreative decisions. They also influence how children born as a result of these procreative decisions in a region with a favourable natural environment and functioning institutions – as opposed to children born elsewhere – contribute in different ways to the society they live in. Differing naturally and humanly constituted environments hence not only may significantly change their

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<sup>213</sup> Del Savio et al. (2018) is a paper that I co-authored with Lorenzo Del Savio and Matteo Mameli on migration and cooperative infrastructures. It is not incorporated into this thesis.

lives<sup>214</sup>, but they also allow them to participate in different ways in the life of the society where they are born and raised, affecting in turn the lives of others born and raised in that society.

These are just a few examples of how the effects of procreative decisions, albeit protected by reproductive freedom, concern many more people than the procreators. They are also examples of how the individual-centred framework to discuss the ethics of procreation fails to account for such effects. It may seem puzzling that having one or more children or that having a child during the Zika virus epidemic has tangible effects on the overall population. It is true that such decisions, taken separately, do not have significant effects. Despite this, as argued by Jonathan Anomaly (2014):

Reproduction is a social act. This is true because the collective upshot of our individual choices shapes the gene pool for all future generations, and because traits that are heritable will impact people who share a common environment.  
(Anomaly 2014: 177)

Similarly, Brock (2005) acknowledges the far-reaching effects of individual procreative decisions and argues that:

*The effect* of many individual decisions, themselves each rational and justified as individual choices, may be collectively undesirable [or desirable] for a group or society. ([emphasis added] Brock 2005: 378)

Considering the effects of these decisions collectively as well as the implications of single procreative decisions on third parties brings to light the limitations of

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<sup>214</sup> Milanovic (2016) uses the expression “citizenship rent” (Milanovic 2016: 5) to describe the phenomenon whereby citizens of high-income countries have an advantage over citizens of low-income countries *irrespective of a citizen’s characteristics and socio-economic status*. Belonging to/living in a country with favourable natural and humanly constituted environments as opposed to belonging to/living in a country with less functioning institutions and less favourable environments changes people’s ‘place premium’ (Clemens 2009), namely it (significantly) changes the expected income of ‘observably identical’ workers of the latter countries compared to workers of the former (Clemens 2009: 2). As we discuss in Del Savio et al. (2018), other than procreation, a phenomenon that changes the structure and the size of the population of a given country is migration, as migrating changes “the cooperative framework within which people can operate and, thereby, it changes people’s ability to contribute to the social production of human goods” (Del Savio et al. 2018: 5).



reproductive freedom and of an individual-centred framework to account for these effects and to reflect on their ethical implications.

I now turn to two proposals for population engineering, one primarily concerned with the structure of the population and the other with its size. I present them and discuss their limitations.

### 3.1 Too Many of a Certain Kind of People and Too Many People

One of the authors who places the emphasis on the quality rather than the quantity of future people is Anomaly (2014, 2018; Anomaly & Boutwell 2017). Anomaly considers procreation to be a social act whose implications have far-reaching effects and argues for the necessity of going beyond an individual-centred understanding of this practice. According to him, procreation needs to be thought of in terms of a public good<sup>215</sup>, one whose benefits and costs are enjoyed and borne by many regardless of their involvement in the production of the good. As he puts it: “parents internalize most of the cost of bearing and raising children, but the returns are widely dispersed” and bearing and raising children has “far-reaching effects on the genetic composition, cultural trajectory, and general welfare of future people” (Anomaly 2014: 172).

Due to these far-reaching effects, procreation needs to be organised in ways which are beneficial both to future people themselves and to those around them. Following Anomaly (2014, 2018), one way of doing so would be to influence the structure of the population by favouring the transmission of traits such as creativity, humour, productivity, intelligence and compassion, which are both beneficial for those who have these traits and for others<sup>216</sup>. Adopting an impartial moral standpoint leads to

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<sup>215</sup> A public good is a good that is both non-rivalrous and non-excludable. This means that if a person enjoys the good, her enjoyment of the good does not prevent others from enjoying the good, and people cannot be excluded from the enjoyment of the good, even if they have not participated in its production. For a discussion of whether children are indeed public good and whether a liberal egalitarian society should offer support to families for raising children, see Serena Olsaretti (2013).

<sup>216</sup> One could challenge the genetic essentialism underpinning these claims and the lack of empirical data in their support. Anomaly (2014) provides some data on the correlation between income and fertility, education and fertility, and IQ and fertility. Granted, this data may be neither valid nor

the conclusion that it is better to bring into the world people who will have good lives and whose lives can contribute to the well-being of others (Anomaly 2014). This means that, all things being equal, the birth of children who have traits which are both beneficial to them and to the community of people around them should be favoured.

Anomaly grants that more people may translate into more producers, more welfare and a larger work force to support an ageing population, but stresses that people are not equally productive<sup>217</sup> and that “some represent a net cost to their society, or to the world” (Anomaly 2014: 176). From this, he concludes that while non-coercive measures to encourage certain people to procreate more and others to procreate less should be preferred over coercive measures, procreation may require government action:

[I]f there is some risk that widely valued traits in the human gene pool are declining, or that the prevalence of some debilitating genetically transmissible disease is increasing. (Anomaly 2014: 182)

Education, subsidised contraception, genetic screening and counselling programmes, incentives for “well-placed parents to have children” (Anomaly 2014: 184) and other ‘soft’ measures should be preferred over sterilisation programmes, licensing programmes (see also: Hickey et al. 2016; LaFollette 1980, 2010) and other more coercive and costly measures.

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While Anomaly is concerned with the structure of the population, other authors are concerned with its size. These authors focus on the different strategies which could be devised to mitigate the negative effects of climate change and to reduce

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sufficient to convincingly make the claim that procreation should be organised according to it. I return to this issue below.

<sup>217</sup> Elsewhere (in Anomaly & Boutwell 2017), Anomaly and Brian Boutwell argue: “Those who urge educated and compassionate citizens in developed countries to have fewer children are missing their target. If their call were heeded, people around the world would be considerably worse off. Imploring people in Spain or Norway to restrict their reproduction does nothing to solve the problem of precipitous population growth in Africa and the Middle East. And it does a lot to impede the development of new ideas, and the creation of value” (Anomaly & Boutwell 2017).

anthropogenic greenhouse gas (GHG) emissions. Rieder (2016) and others (Das Gupta 2014; Hickey et al. 2016; Murtaugh & Schlax 2008) contend that the most effective way to reduce such emissions is to decrease the size of the population by changing people's procreative behaviours, as procreation plays an important role with respect of the quantity of GHG emissions<sup>218</sup> (Harte 2007; Murtaugh & Schlax 2008; Nolt 2011). The effects of climate change on people's well-being call, in their view, for *pro tanto* moral reasons to refrain from procreation or, at least, for reducing the number of children being born. For instance, Rieder (2016) argues that people have "procreation-limiting duties" (Rieder 2016: 9) as:

There are too many people on earth, together emitting too much GHG much too quickly. [...] The public health crisis of overpopulation leads to the intuitive conclusion that morality might demand of each of us that we do not contribute to such a crisis. (Rieder 2016: 10)

Rieder (2016), Anomaly (2014) and other authors advocating for population engineering are aware of the relevance of freedom in matters of procreation for people's personal autonomy and well-being, and of how protecting people's reproductive freedom amounts to protecting morally relevant individual interests. They advocate for measures which seek to address the challenges of the far-reaching effects of individual procreative decisions, but they are cautious as to the potential negative externalities of curtailing people's freedom. They also adopt different strategies to address the tension between the interests (and the freedom) of

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<sup>218</sup> Procreation has an impact on climate change: creating one more person generates immediate effects on GHG emissions (think about the bigger car and house, and larger quantity of food and water etc. required after the birth of a child), and long-term effects (that child will eventually become an adult who consumes, pollutes, and, above all, might well procreate thereby creating new consumers and polluters). Studies such as those by Paul A. Murtaugh and Michal G. Schlax (2008) and John Nolt (2011) show how the total of CO<sub>2</sub> emissions saved by refraining from bringing one more child into the world is significantly larger than the total of life-time savings of other common activities aimed at reducing CO<sub>2</sub> emissions such as recycling, decreasing carbon footprints, increasing the energy saving efficiency of people's homes, etc. Also, the type of person we go on to create will contribute to a different extent to GHG emissions. This can be approximately calculated on the basis of the differing rates of GHG emission per country (Hickey et al. 2016; Murtaugh & Schlax 2008; Nolt 2011; Rieder 2016). These views are challenged by those arguing that is not net population growth (or number of people inhabiting the planet) that causes increased GHG emissions, but rather the systems of production of goods and the ways these systems are organised (see for instance: Angus & Butler 2011).

individual procreators and the interests of other people. Rieder (2016), for instance, argues that there is more to morality than what is within one's rights and that acting within these rights does not necessarily translate into acting in the morally right, viz virtuous, manner. He contends that acting *rightly* entails reducing one's own family size even if this is at odds with one's own rights. Anomaly (2014) instead focuses on the potential challenges and costs that even non-coercive measures to carry out population engineering programmes might engender when state institutions are involved in such programmes. According to the author:

There are three main reasons for caution in moving from social norms that nudge people to make socially beneficial reproductive choices, to using state institutions that shape reproductive choices. The first is that the science of genetics is still in its infancy, and our ability to manipulate genetically mediated traits is not yet sophisticated. The second is the value of individual autonomy, or the (defeasible) right to control one's own reproductive choices. The third reason for caution is that agents of the state will always possess imperfect information and often face perverse incentives.<sup>219</sup> (Anomaly 2014: 182)<sup>220</sup>

The knowledge of how genes influence behavioural traits such as empathy and intelligence (or even aesthetic traits such as eye colour or height) and the capacity to edit genes to favour the expression of these traits are in their infancy to say the least. Despite this, I would argue, following Anomaly, the current lack of knowledge may not represent per se an insurmountable challenge to carrying out population engineering programmes. It may also not represent, as it were, an insurmountable (ethical) argument against these programmes. Studies on the heritability of IQ date back to the beginning of the 20<sup>th</sup> century and some progress has been made (for a review, see for instance: Ritchie 2015). Moreover, if it becomes clear that population engineering and Anomaly's aims of improving the structure of the

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<sup>219</sup> Even though Anomaly mentions the potential challenges arising from carrying out population engineering programmes, he does not elaborate on them.

<sup>220</sup> I discuss these reasons for caution below. Contrary to Anomaly (2014), in my view caution is required not only when population engineering programmes are coercively carried out by the state. What he refers to as 'social norms that nudge people', albeit less coercive, can have as ethically troubling effects as state-driven programmes.

population can be achieved not through prenatal/pre-conception genetic interventions but thanks to controlled epigenetic influence, education, welfare provisions and other postnatal measures, then the question of the desirability and ethical standing of population engineering programmes will remain. In other words, the first reason for caution identified by Anomaly (2014) is a problem that can be conceived as contingent. With respect to the second reason for caution (the value of reproductive freedom), it is important to consider that even liberal defences of reproductive freedom allow some degree of interference from third parties to protect children's interests and/or to limit harm to others (Brock 2005; Dworkin 1994). The question of protecting reproductive freedom would then turn into the question of whether harms engendered by what this principle protects warrant some kind of restriction on people's procreative decisions, even considering the costs of curtailing their freedom. This needs to be discussed while bearing in mind also the third reason for caution identified by Anomaly (2014), namely the risk that third parties may possess "imperfect information" and may be faced with "perverse incentives" (Anomaly 2014: 182).

The remainder of this final part of the thesis revolves around the question of whether ethical frameworks which consider the far-reaching effects of procreative decisions such as those just presented should be preferred to the individual-centred framework of reproductive freedom, considering these reasons for caution, and it assesses the strengths and weaknesses of said alternative frameworks. But first, I turn back to eugenics and Malthusianism, as they represent historical examples of population engineering programmes which adopted a framework to reflect on and to organise procreation that considered the far-reaching and cumulative effects of procreative decisions.

#### **4 A Broader Framework: Lessons from the Past**

Proposals to enact population engineering programmes and to reflect on procreation in ways that take into account the interests of other people than the procreators recall movements, thinkers, ideologies, policies, and practices of the past: Malthusianism and eugenics (see also: Connelly 2008; Bashford 2014). As

mentioned above, while the emphasis within Malthusianism was primarily on the size of the population, within eugenics it was primarily on the structure. I discuss these movements jointly in this section: both Malthusianism and eugenics fit the description outlined above of population engineering programmes. Moreover, both within Malthusianism and eugenics, procreation was conceived as a phenomenon that could be subjected to external control as it was a social act, an act with social, political, and moral dimensions that transcended those who executed it<sup>221</sup>.

Malthusianism was inspired by the work of Reverend Thomas Robert Malthus and was chiefly concerned with the risk of food scarcity and famine. Malthus and his followers believed that whilst the population grew exponentially, food supply grew arithmetically. This disparity in the growth rates of food and population motivated the perceived need to put into place population-control measures to avoid widespread famine and diseases: the Malthusian catastrophe (Mayhew 2016). These concerns were also at the heart of the modern environmentalist movement of the 60s and 70s (Angus & Butler 2011). During that time, some of the key issues debated by authors advocating for the type of population engineering described above began to emerge and to be a matter of concern for activists and scholars alike. Their views were of marked Malthusian orientation: mass starvation was seen as inevitable and rapidly approaching, and the environment was perceived as being doomed to gradually deteriorate and be rendered inhospitable. For some authors, the origin of all these catastrophes was the uncontrolled growth of the population (for a discussion, see: Angus & Butler 2011; Bashford 2014; Connelly 2008). These were also the central theses of Paul (and Anne) Ehrlich's *The Population Bomb* (Ehrlich 1968). Similar worries were echoed by Garrett Hardin<sup>222</sup>, author of *The Tragedy of the*

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<sup>221</sup> For a discussion of the relationship between Malthusianism and eugenics today, see for instance: Susanne Klausen and Alison Bashford (2010).

<sup>222</sup> As Ian Angus and Simon Butler (2011) show, Hardin was also a eugenicist who wrote: "Studies indicate that as long as our present social organization continues, there will be a slow but continuous downward trend in the average intelligence—there seems to be little danger of society's being deprived of something valuable by the sterilization of all feeble-minded individuals—more spectacular results could be obtained by preventing the breeding of numerous members of the subnormal classes higher than the feeble-minded" (Hardin 1949: 611-612, quoted in Angus & Butler 2011, Ch 9).

*Commons* (Hardin 1968) and of the essay “Lifeboat Ethics: The Case Against Helping the Poor” (Hardin 1974). There, Hardin (1974) employed the metaphor of a lifeboat to describe the U.S. He believed that ‘taking on board’ those who were drowning, namely people from developing countries trying to immigrate to the U.S., would have doomed the ‘lifeboat to sink’. While Ehrlich (1968) worried about population growth and advocated for birth control measures, Hardin (1974) was chiefly concerned by immigration fluxes and how they could exacerbate the draining of American resources. Malthusian themes and worries also influenced the ‘father’ of bioethics Van Rensselaer Potter. Potter (1971, 1988) identified in population growth and especially in the prevention of overpopulation both a challenge and a priority for bioethics (see also: ten Have 2012). According to Potter (1971), controlling population growth was necessary to ensure the long-term survival of the human species<sup>223</sup>, the challenge for and aim of bioethics.

As discussed in Paper 1 (Cavaliere 2018d), eugenics- (and Malthusianism-)inspired population engineering programmes of the past were constituted by a diverse range of practices, policies, ideologies, movements and thinkers (Adams 1990; Bashford 2014; Bashford & Levine 2010; Connelly 2008; Meloni 2016). Part of the long history of attempts to engineer the population are negative interventions such as forced sterilisations of people of colour and of the so-called ‘feeble-minded’ in the U.S. (Kevles 1985; Roberts 1997) and Scandinavian countries (Broberg & Roll-Hansen 2005); atrocities such as those committed during the Nazi Aktion T4 programme (Adams 1990; Buchanan et al. 2001); immigration policies aimed at selectively accepting immigrants depending on their geographic and racial origins (Kevles 1985); feminist advocacies for free distribution of birth control domestically (Roberts 1997) and internationally (Murphy 2017); and socialist-parties’ attempts to re-organise the welfare state by limiting certain groups’ procreative decisions (Koch 2004; Paul 1984). Part of this long history are also positive interventions aimed at favouring the birth of strong and healthy individuals such as the American fitter

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<sup>223</sup> Despite exploring different avenues to reducing population growth (both coercive and non-coercive in nature), Potter seems ambivalent about how this challenge should be addressed (see also: ten Have 2012).

family contests (Lombardo 2008), ante-natal clinics, school inspection services and free school meals (Porter 2005). Despite these variations in terms of ideologies, measures, policies and practices, the idea of changing the size and structure of the population in ways that would favour economic production (Murphy 2017), relieve poverty (Roberts 1997) and allow the breeding of a better human stock through positive and negative interventions were shared features of these differing endeavours.

As the work of historians such as Löwy (2015, 2018), Bashford (2010, 2014) and Paul (1984, 2017) testifies, the focus on population-wide interventions and modes of thinking characteristic of Malthusianism and eugenics survives within discourses on PND and prenatal screening (see also Mills 2015 and Buchanan et al. 2001). On the one hand, there are the demands of women, their wish to play an active role in decisions pertaining to who should come into existence and discourses of ‘choice’<sup>224</sup>. On the other, there are the aspirations of public health professionals of favouring the birth of healthy children who will grow into adults who can contribute to society and the recognition that procreative decisions have social consequences (Löwy 2015; Paul 2017). In Löwy’s (2015) words:

Numerous women wish to avoid a birth of a child with Down’s syndrome but the implementation of regional and national screening programmes was a top-down, not a bottom-up, process. Moreover, this process was shaped by two incommensurable ‘moral economies’—or to follow Boltanski and Thevenot’s expression, two ‘worlds of worth’ (‘mondes de valeur’)—that shaped this technology, that of gynaecologists and obstetricians, committed to ethics of individual-centered medicine, and that of public health experts and

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<sup>224</sup> As Löwy (2015) argues, this “user demand argument” (Löwy 2015: 195) is an accurate depiction of the rationales for offering prenatal diagnosis only at a certain time in history. At its inception, in the 60s and 70s, PND was offered to women who, due to the birth of an affected child, were aware that they could pass genetic conditions to their offspring and were “concerned about the possibility of giving birth to a second affected child” (Löwy 2015: 195). Later on, however, healthcare professionals began to educate women about the link between maternal age and the increased risk of having children with Down’s syndrome. According to Löwy (2015), then, the user demand argument applies less to these kinds of interventions and rationales for offering PND. Mills (2015) points to something similar when she argues that both freedom and certain norms about health and diseases became normalised within discourses on prenatal testing and screening.



administrators, who reason in terms of the cost/efficacy of health measures.  
(Löwy 2015: 199)

Buchanan et al. (2001) identify this duplicity in terms of the tension between individual and broader interests as a defining characteristic of eugenics, but also of today's public health interventions. By and large, this tension and duplicity survive in the work of authors advocating for different kinds of population engineering and interventions in procreation. As discussed in Paper 1, they also survive in the arguments in favour of and against new reproductive technologies.

### 4.1 What Was Wrong?

In their 'autopsy of eugenics', Buchanan and his co-authors (2001) consider five theses to address the question of why eugenics was wrong<sup>225</sup>. After a careful analysis of them, they conclude that the chief wrong of eugenics was not that its focus was on social and not individual interests but rather that it failed to fairly distribute the burdens and benefits of exercising control over procreation:

The eugenics movements of 1870-1950 insisted – wrongly, as it turned out – that humankind faced a grave threat (degeneration) and stood to gain a large benefit (more able, fit people) if humans would submit to the kind of breeding programs that had been used to improve plants and livestock. But who would benefit and at whose expenses? [...] The 'underclass' is simultaneously the group of people whose genes were not wanted and the people who, through involuntary sexual segregation, stigmatization and denigration, sterilization, and even murder, paid the price. (Buchanan et al. 2001: 52)

Hence, they conclude:

The key issue in appraising the shadow cast by the eugenics movements on clinical genetics is not whether those who build programs of clinical genetics

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<sup>225</sup> The theses are: eugenics was wrong because it was about replacing people, i.e. causing better people to come into existence, rather than treating existing people. Eugenics was wrong because it lacked a consideration for the pluralism of ideals and values. Instead, it promoted "a particular conception of human perfection" (Buchanan et al. 2001: 48). Eugenics was wrong because it violated people's reproductive freedom. Eugenics was wrong because it entailed an unfair distribution of burdens and benefits (Buchanan et al. 2001: 46-52). See also: Daniel Wikler (1999) on this issue.

## Part IV: Back to Eugenics

have an individual focus as opposed to a social one. *The social goal is not automatically suspect. What matters is whether either goal is pursued justly.* ([emphasis added] Buchanan et al. 2001: 55)

Population engineering programmes of the past were designed in such ways that the burdens would systematically fall on certain groups, such as ethnic minorities, disabled people, poor people and immigrants, while the benefits of these programmes would be enjoyed mostly by the rich and the educated, many of whom were white. At the heart of these programmes and of the unjust distribution of their burdens and benefits, were epistemic and political problems which should be considered within any contemporary attempt to organise procreation in ways aiming to consider the interests of other people than the procreators and their close networks.

These epistemic and political problems can be traced back, on the one hand, to how beliefs on the differential economic worth of people for society translated into beliefs of the differential moral worth of these people (Murphy 2017); on the other, to how they translated into problematic and often misguided beliefs of the science of heredity (Meloni 2016). Past population engineering programmes aimed at enhancing GDP (Murphy 2017) or at relieving poverty among black minorities in developed countries (Roberts 1997) disproportionally targeted and affected people from the lower classes of developed countries and people living in developing countries. These programmes targeted, as Murphy puts it, “the future generations of the precarious” (Murphy 2017: 93), which became designated as “a kind of surplus life: sacrificeable and unvaluable to the economy, thus better never to have been born” (Murphy 2017: 93). These beliefs found justification in a view of heredity that Meloni (2016) defines as ‘radical biologism’, which:

[F]lattened the notion of the human and its psycho-cultural manifestations into its merely biological dimension. Even mental and moral qualities were seen as aspects of the hereditary mechanism. (Meloni 2016: 66)

Manifestations of pauperism, disability and precariousness were linked to biological characteristics and hence considered heritable. These epistemically flawed beliefs

served as a source of inspiration for policies and, at the same time, resonated with extant racist, sexist and ableist political beliefs (Meloni 2016; Porter 2005, Ch 10).

That epistemically and politically troubling beliefs can give rise to ethically troubling strategies for intervening in procreation and to the unjust distribution of the burdens and benefits mentioned above is, in my view, one of the most important lessons that population engineering programmes of the past can teach us. This lesson is relevant for authors advocating for population engineering programmes today. It is also relevant to assessing whether reproductive freedom and the individual-centred framework that underpins it is preferable to the framework that informs the proposals of these authors. It remains open for today's discussions whether all attempts to conceive procreation more broadly and to act upon this conception are bound to re-enact wrongs akin to those of the past<sup>226</sup>.

## 5 Taking Issue with Alternative Frameworks: Harm to Others, Structure, and Size

At the end of the section on reproductive freedom, I argued that the relevant question concerning the ethics of procreation is whether an alternative framework that considers the interests of other people than the procreators is preferable to the individual-centred framework of reproductive freedom. In this last section, I explore this question in light of the epistemic and political problems which caused an unjust distribution of burdens and benefits in past attempts to reflect on procreation. I first outline some of the shortcomings of the challenges raised against the individual-centred framework by authors concerned with potential harm to third parties (such as ethnic minorities, women and disabled people). I then move to the shortcomings

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<sup>226</sup> Many authors argue that all attempts are bound to go wrong, but give different reasons for this view. Some adopt a libertarian framework and condemn *any* (or most of) state intervention in procreation due to the violation of people's fundamental negative rights (see for instance Harris 1998). Others instead consider attempts to constrain and organise procreation as a violation of what is naturally given and as a corruption of the intrinsic value of 'natural' reproduction (see for instance Sandel 2004a). I find these approaches unsatisfactory. The libertarian approach is unsatisfactory insofar as it does not account for violations of freedom which do not directly depend on curtailing negative rights and insofar as it leaves social injustice untouched (Roberts 1997). The intrinsic value approach is also unsatisfactory, as its defence of the intrinsic value of natural reproduction is often question-begging (Buchanan 2011).

of the challenges to the individual-centred framework motivated respectively by a concern for the structure and the size of the population.

### 5.1 Harm to Others and Levelling Down

Different avenues could be explored to reduce or eliminate the occurrence of harm to third parties. Devaluing black mothers (Roberts 1997), disabled people (Garland-Thompson 2012) and women more generally (de Melo-Martín 2017a) is something that needs to be avoided. Despite this, curtailing (everyone's) reproductive freedom to minimise its negative externalities on these groups seems to be problematic too. Rather than curtailing the freedom of certain groups to avoid harming other groups, two alternative strategies could be trialled: one could factor in the costs and the benefits of reproductive freedom and equally distribute *both* these costs and benefits. This means that for instance devaluing people should be factored against the costs of reducing people's reproductive freedom in ways that, following Buchanan et al. (2001), justly distributes these burdens and benefits of reproductive freedom. Alternatively, one could first try to extend the benefits and especially the reach of reproductive freedom to others who hitherto have not enjoyed it and work towards removing the barriers<sup>227</sup> to this enjoyment. This would entail 'levelling up' the reach of reproductive freedom prior to advocating for its 'levelling down' in cases where the benefits cannot be properly extended or in cases where the overall burdens are too great. It seems that the authors who challenge the individual-centred framework of reproductive freedom due to its ability to incur potential and actual harm to third parties focus on levelling down while failing to first explore strategies aimed at levelling up. More on this in the next section, but this is what I take to be the main shortcoming of challenges to the individual-centred framework motivated by a concern for harming third parties.

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<sup>227</sup> This would not only entail limiting or eliminating third-parties' interference and working towards state-neutrality in procreative matters but also working towards the removal of barriers which are due to cultural and socio-economic reasons, as well as discrimination of the kind denounced by Roberts (1997), Murphy (2017) and disability scholars such as Garland-Thompson (2012).

I now turn to what I consider the shortcomings of contemporary proposals to manipulate the size and structure of the population: such as Rieder's (2016), Anomaly's (2014, 2018) and others' (Hickey et al. 2016).

## 5.2 The Problem with Engineering the Population: Structure and Size

I identify two main shortcomings of population engineering programmes and proposals: acquiring reliable data on who should come into existence and assessing this data. With respect to programmes aimed at tackling the structure of the population, the first shortcoming concerns the feasibility of acquiring data on the type of people who could be reliably said to contribute to overall increases in the well-being of future people. Anomaly (2014) argues that the best suited to become parents are those with "favorable genetic endowment" and "the means to provide a rich social environment for their children" (Anomaly 2014: 174), as both characteristics seem to predict the birth of people whose lives have value both for themselves and for others. However, what counts as favourable genetic endowment and as a rich social environment is a complex notion: whether a given genetic endowment really turns out to be favourable often depends *also* on people's social environments. In this sense, the assessment of what counts as favourable genetic endowment cannot be separated from the assessment of what counts as a rich social environment. Not only are these conditions often context-dependent, they are also normatively loaded as what counts as 'favourable' and 'rich' presupposes the adoption of a certain normative framework as a reference. In other words, in an assessment of whether something is rich or favourable, the impartial moral standpoint will not do. Different groups of people are likely to come up with different assessments of what counts as valuable and competing interests are likely to play a role in these assessments.

This brings me to the second shortcoming. If I am right about the first, there will be competing assessments of what counts as valuable and different answers to the question of what type of people should be allowed to come into existence. Hence, a reliable mechanism to acquire empirical data that can assist in the selection of the best answers to ground future policies becomes necessary. Acquiring this data

currently seems again normatively loaded and complex: this data could reflect our current 'status quo' biases (Bostrom & Ord 2006), current racist and discriminatory attitudes (Roberts 1997, 2015) and current short-sighted or partial conceptions of valuable lives (Garland-Thompson 2012; Mackenzie & Scully 2007). As Kitcher (2001) puts it:

[An] analytical study of the methods of trying to show genetic differences in intelligence brings out what would be required to support responsible conclusions; examination of ventures in human sociobiology exposes how hard it would be to do it properly. (Kitcher 2001: 99)

There have been studies on the heritability of IQ (for an overview, see for instance: Ritchie 2015) and studies that correlate high IQ and low fertility (Meisenberg 2009). Despite this, delving into the history of research on the mechanisms of human heredity allows us to appreciate that there exists a complicated interplay between epistemic and political forces: between the quest for knowledge and interventions acting upon that knowledge (Meloni 2016; Roberts 2015). The type of questions asked, the hypotheses formulated, the data collected and the inferences drawn are all likely to be influenced by existing political views and beliefs. In addition, it is unclear who should decide what data is to be taken into consideration for institutional design and whose normative framework should be used as a reference. Should this framework reflect the values of everyone or just of selected groups? How would this framework be delineated? Through a majority vote or by a group of experts? What kind of expertise can assist in these decisions? The problem, then, is not (or not only) about 'imperfect information' and 'perverse incentives' possessed by the state, but rather about the difficulty of having reliable mechanisms to assess this information both in the context of state interventions and of shaping social norms.

Regarding the size of the population, it may seem that population engineering programmes might be less problematic and that the challenges outlined above might not apply. Economic growth, increased levels of welfare, better educational provision and institutions are all viable strategies to reduce fertility rates (Sen 1994). Despite this, the one-size-fits-all model to reduce the size of the population seems to

be ill-conceived if the aim is to reduce for example climate change hazards (as noted for instance by: Anomaly & Boutwell 2017; Haraway 2016; Rieder 2016). Not all people contribute equally to the worsening of climate change (Rieder 2016; Murtaugh & Schlax 2008) and not all people are in an equal position to produce new resources to confront these negative effects (Anomaly & Boutwell 2017). Hence, it seems reasonable to assume that it would be self-defeating to implement measures which seek to reduce everyone's birth rates: population engineering programmes aimed at reducing the size of the population cannot be equally applied to everyone because this will not yield the expected results (reducing GHG emissions and mitigating the effects of climate change). Population engineering programmes aimed at reducing the size of the population cannot be easily disentangled from population engineering programmes aimed at influencing the structure of the population. The two (i.e. size and structure) cannot be completely separated today, and they were not completely separated in the past (Bashford 2014; Connelly 2008; Klausen & Bashford 2010). Contemporary attempts to reduce the size of the population are likely to incur the very same shortcomings identified above, as competing interests are likely to influence people's assessments of what counts as valuable (i.e. who should procreate and how much) and the decision of who gets to decide in these matters influences which interests will be given priority.

## 6 Conclusions to Part IV: Settling with What We Have?

It seems that both the individual-centred framework of reproductive freedom and alternative frameworks<sup>228</sup> which take into account the interests of a broader set of people present some limitations. The question of whether a framework that considers the interests of other people than the procreators or whether an individual-centred framework is better suited to reflect on the ethics of procreative decisions remains open. In my view, despite critiques and challenges, both frameworks present strengths and weaknesses and neither should be dismissed without careful

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<sup>228</sup> Here, I refer to the frameworks of reference of those criticising reproductive freedom for its limited reach and for the harms it engenders to certain groups as well as that of those advocating for some form of population engineering programme.

consideration of what it could help achieve both in terms of theoretical contribution and practical significance.

With respect to the individual-centred framework, the recognition of the relationship between exercising freedom in matters of procreation and people's autonomy and well-being counts as one of today's greatest achievements<sup>229</sup>. It also counts among the greatest safeguards against forms of interference which may undermine people's personal autonomy and negatively affect their well-being. Indeed, contemporary critiques of eugenics are often motivated by its lack of concern for bodily autonomy, integrity and respect for people's freedom in matters of procreation. With respect to broader frameworks, I would argue that, despite the shortcomings identified above, procreation can neither be considered a matter that solely concerns individual procreators nor a matter that solely affects them. In this sense, I agree with the proponents of population engineering programmes and those concerned with harms to third parties, public goods, climate change, migrations, an ageing population and other global trends that an individual-centred framework is too narrow to account for the cumulative and far-reaching effects of procreative decisions. Considering the interests of others and of how procreation contributes to shaping the structure and size of the population may be a starting point to foster conversations and devise strategies to minimise negative effects on third parties and to address these global challenges and trends. All this is unlikely to happen if we remain solely concerned with procreators' interests and with non-interference from third parties.

Would it be possible to combine the strengths of both frameworks whilst minimising potential negative outcomes? Ergo, would it be possible to reflect on procreation and take into account a broad set of interests while on the one hand respecting and promoting people's freedom in matters of procreation and on the other fairly

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<sup>229</sup> This neither means that such a relationship is universally recognised nor that countries that do not recognise it need to be looked down upon. The reasons why reproductive freedom became ethically relevant in certain contexts and not in others has to do with complex political, cultural and social factors which are not explored in this thesis.



distributing the burdens and benefits of procreative decisions? Here are some preliminary thoughts.

One way would be to settle with what we have (and have achieved) and to strive to address the limitations of reproductive freedom and the individual-centred framework. In other words, if we are really committed to respecting and promoting freedom in matters of procreation as we recognise the significance of this freedom for people's lives and the costs of foregoing its enjoyment, then it seems puzzling to be in favour of the exercise of such freedom only for some restricted groups. Part of a possible solution to the limitations of the reproductive freedom framework would then be to work towards inclusivity in freedom to enable ever broader groups to enjoy it. Defending and promoting reproductive freedom will have to be an endeavour that seeks to extend its enjoyment to those who currently do not enjoy it. It would entail working towards removing barriers to this enjoyment which are not only caused by statutory bans or restrictions on the part of the state but by social, financial and cultural barriers, and by lingering discriminatory attitudes. Given the importance of personal autonomy and well-being, this seems to me an ethical way forward both for debates on the ethics of procreation, where the focus should shift from non-interference and negative freedom to inclusivity in freedom, and for the enactment of strategies to extend this freedom beyond the groups currently able to enjoy it.

Despite this, broadening reproductive freedom and extending its reach does not address some of the challenges identified by those who advocate for population engineering programmes due to the negative externalities of people's procreative decisions. There may be cases, therefore, where extending reproductive freedom's reach may either not be possible or may engender negative effects on third parties. With respect to this, any programme of population engineering would have to address challenges raised by what, following Kitcher (2001), I refer to as political and epistemic asymmetries. According to Kitcher, political asymmetry occurs if a) empirical data that supports certain lingering sexist or racist beliefs leads to a reversion to a situation in which these beliefs were widespread, while empirical data that contradicts these lingering beliefs does not lead to a further eradication of these

beliefs; and if b) empirical data that supports certain lingering sexist or racist beliefs leads to the worsening of certain racial groups' or of women's lives, while empirical data that contradicts these lingering beliefs does not lead to notable improvements for these groups (Kitcher 2001: 97). Epistemic asymmetry occurs instead when certain studies and certain conclusions, theories and data, despite being assigned low reliability, will be taken more seriously than they should be (considering the low reliability) if they resonate with widespread racist and sexist beliefs<sup>230</sup>. Population engineering programmes may end up constraining or influencing people's procreative decisions and tampering with their reproductive freedom. Due to the relevance of procreation for people's well-being and due to the tainted history of attempts to engineer the population, it is necessary to develop reliable strategies to make sure that political and epistemic asymmetries do not persist. This is the case as when the stakes are so high, "standards of evidence must go up" (Kitcher 2001: 96).

The history of population engineering programmes reminds us that people from the worse-off segments of society, women, ethnic minorities, etc., have been unduly and disproportionately carrying the burdens of these. If residual discriminatory attitudes towards these groups persist, then contemporary proposals of manipulating the size and structure of the population risk giving rise to similarly problematic outcomes. The question of whether *all* attempts to conceive procreation more broadly and to act upon this conception are bound to fail remains open.

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<sup>230</sup> More precisely, according to Kitcher, epistemic asymmetry occurs when three conditions are met: a) "There will be significant differences between the probabilities assigned to the hypothesis that people with *C* are less well-suited to *R* and the probabilities that would be assigned by using the most reliable methods for assessing evidence; the probabilities assigned to the hypothesis by members of the society will typically exceed the probabilities that reliable methods would yield, and the probabilities assigned to the negation of the hypothesis will be correspondingly deflated."; b) "With high probability, the evidence obtained from pursuit of *S* will be indecisive, in that the most reliable methods of assessing that evidence would assign a probability of roughly 0.5 to the hypothesis."; and c) "The bias in favor of the hypothesis is so strong that most members of the society will take evidence that, when assessed by the most reliable methods, would yield a probability for the hypothesis of roughly 0.5 to confer a probability close to 1 on the hypothesis." (Kitcher 2001: 97-98)

# CONCLUSION

This thesis began and ends with eugenics. It began with questions raised by new reproductive technologies, by their clinical applications, and by different strategies that can be pursued to regulate them. It ended with questions raised by procreative decisions, by the far-reaching effects of procreation, and by theorisations of population engineering programmes. It has been my argument throughout this thesis that new reproductive technologies and procreative decisions make us face questions concerning who should come into existence, and how to balance the burdens and benefits of such decisions. In other words, we are faced with questions concerning the ethics of eugenics.

The research that led to this thesis sought to address questions pertaining to the ethics of eugenics and to pursue two overarching aims. From a methodological point of view, this study has taken as a point of departure a cluster of critiques and proposals for bringing bioethics forward (the idea of ‘critical bioethics’) and has gone beyond them. It seeks to contribute to debates on the ethics of new reproductive technologies and of procreative decisions by providing arguments for, and examples of how they should be informed by other disciplinary sources than moral philosophy; the benefits of adopting a self-reflective attitude; and of exercising polite scepticism. Throughout this thesis and to work towards this methodologically-oriented aim, debates on the ethics of eugenics have been treated as case studies and examples. The other aim of this project concerns, more specifically, ethical questions raised by new reproductive technologies and procreative decisions. This study has three goals: providing arguments for making these technologies more widely accessible; for regulating these technologies and reflecting on ways to organise procreation in order to fairly distribute their burdens and benefits; and for implementing new reproductive technologies in ways which respect the plurality of values and world-views surrounding them.

## 1 Taking Stock: Back to the Research Questions

Several questions guided the research that led to this thesis. The first set of questions pertains to a reflection on debates on the ethics of new reproductive technologies and procreative decisions. Within these debates, eugenics is both a recurring reference and a widely employed rhetorical tool. New reproductive technologies, applications of these technologies, and proposals to implement them are often juxtaposed with eugenics. This move serves to condemn these technologies and their applications by making analogies with eugenics or to defend them by using dis-analogies between past and present. Often, the reference to eugenics is devoid of engagement with the complexities of its history and it becomes a means to express unease (for some) or unquestioning acceptance (for others). Eugenics and its history replace arguments and reflections on ethical challenges raised by new reproductive technologies. As a result, debates on these technologies are transformed into debates on whether these technologies are eugenic or not and on the implications of labelling them as such. But these debates, prior to being about the past and the present, are about negotiating conflicting values and conflicting answers to the question of who should come into existence. These disputes are not likely to be resolved by settling once and for all the question of whether new technologies are indeed eugenic. They are not likely to be solved as the more profound disagreement lies within the ethical standing of eugenic decisions, both past and present. Following Paul (1992), I have argued that eugenics should not be treated as a cautionary tale and that the references to its history should not be employed lightly within debates on the ethics of new reproductive technologies. In this sense, it would be constructive to adopt a self-reflective attitude to which characteristics of both eugenics and new technologies motivate one's own comparison between past and present. In addition, partial accounts of the history will neither contribute to debates on the ethics of new reproductive technologies nor foster constructive exchanges on the ethical questions raised by these technologies.

Other than references to eugenics, moral disagreement is another core characteristic of debates on the ethics of new reproductive technologies. It may be tempting to interpret such disagreement only in terms of conflicting assessments of the benefits,

the risks, and the safety of a certain technology. It may be tempting, but this interpretation should be resisted: assessments of safety, risks, and benefits are not only about empirically demonstrable (and universally agreeable) facts. These assessments are informed by moral beliefs, by one's position in society, and by the capacity to reap the benefits or bear the burdens of new technologies. I have argued that how disagreement should be dealt with within debates on new reproductive technologies depends on the aims of these debates. Focusing on refining arguments and sharpening one's own philosophical reflections (and those of other authors participating in these debates) is an endeavour worth pursuing, but it might not provide a sound starting point for suggesting strategies to regulate these technologies. In other words, whether disagreement hinders or helps depends on what debates on the ethics of new reproductive technologies collectively and individually want to achieve. This is a question that to a certain extent remains open but that, in my view, needs to be discussed. Reflecting on what these debates (and one's role within them) ought to achieve can help to refine one's questions and argumentative strategies, and to work towards specific goals.

Moving from discussions about the ethics of new reproductive technologies to discussions about procreative decisions, I have presented and assessed what I believe to be some of the shortcomings of an ethical framework that focuses solely on individual procreators. This framework, which I have argued underpins reproductive freedom, is problematic insofar as it does not account for the far-reaching and cumulative effects of procreative decisions. It fails to provide a common ground where trade-offs between benefits and burdens (and who should reap or bear them) can be discussed. Once again, eugenics plays a role in these reflections. Within 20<sup>th</sup> century eugenics, procreation was thought to be a matter that transcended individual interests and collectively affected third parties. The tension between individual interests and the common good was dealt with in ways disproportionately affecting and discriminating against certain groups. It was dealt with in ways that did not, following Buchanan et al. (2001), fairly distribute the burdens and benefits of attempts to engineer the population. If eugenics was the disease, reproductive freedom became the cure (see also Agar 2008). Unfortunately, along the way the relevant features of, and lessons from eugenics have been lost.

Eugenics represents a first, albeit ethically problematic and engendering troubling outcomes, instance of thinking broadly about procreation. Attempts to rethink the ethics of procreative decisions need to consider what could go wrong now if residual discriminatory attitudes continue to pervade our society.

A second set of research questions guiding my project focuses more specifically on the ethics of new reproductive technologies and procreative decisions (rather than on discussions about them). Considering the wealth of ethical questions engendered by these technologies and procreative decisions, my analyses in the papers incorporated into this thesis have been circumscribed to two main, related questions. The first question concerns what weight the preference to have genetically related children should be given; the second concerns what limits, if any, should be imposed on the satisfaction of people's interests in procreative matters. One of the main rationales behind the development of ever newer reproductive technologies is prospective parents' desire to have children who are genetically related to them (or partially genetically related to them) and healthy (or healthier than these children would otherwise have been were these technologies not employed). IVF, PGD, MRTs, but also genome editing and other technologies discussed in this thesis, fit this description and these rationales. Authors who criticise new reproductive technologies often object to the deployment of resources to develop new reproductive technologies to satisfy the preference to have genetically related children. They also dismiss and criticise this preference as the result of ethically troubling parental attitudes, false consciousness, and genetic essentialism, among other reasons. While it is of fundamental importance to question the value of genetic relatedness and the preference to have genetically related children within debates on new reproductive technologies, I have argued that it does not stand as a defeating objection to these technologies. This would be too facile. Too often this objection overlooks the costs of not satisfying this preference for people's autonomy and well-being, and how these costs systematically fall on certain groups (who cannot have children for social, medical, legal, and other reasons) as opposed to others. Not all reproductive technologies should be developed, not all resources deployed, and not all preferences satisfied. Despite this, dismissing this preference should be preceded by balancing the costs and benefits, in which not only the costs of satisfying this

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preference should factor but also those of not satisfying it. Something similar can be said about the interests of procreators. Individual-centred frameworks such as that underlying reproductive freedom do well in protecting people's (i.e. the procreators') interests and in focusing the attention on their relevance for people's autonomy and well-being; they do less well in capturing other aspects, consequences, and implications of procreative decisions. Reflecting on procreative decisions by broadening the framework to capture the far-reaching and cumulative effects of these decisions, as discussed above, could be a starting point to limiting the negative externalities of said decisions.

The third and final set of research questions concerns the governance of new reproductive technologies. These questions have guided my evaluation of different regulatory approaches against their capacity to accommodate the multiplicity of values and world-views coexisting within the societies where these technologies are discussed, developed, and implemented. Moral disagreement is a core characteristic of debates on the ethics of new reproductive technologies and such disagreement extends to ethical-political questions concerning how to regulate these technologies and who should decide how to do so. By and large, these questions raise broader issues such as what weight should be given to people's values and ethical views on embryo research, genome editing, and other technologies in practice, as well as what respecting these values and views entails.

Drawing on the debate on whether to extend the 14-day limit for embryo research and whether to allow genome editing applications to early human embryos, I have argued that some of the conflicting values and beliefs concerning these technologies can be explained by the idea of value pluralism, which offers both an explanation for moral disagreement as well as a normative reason to respect conflicting ethical views (Wolf 1992). It offers an explanation as to why authors participating in debates on the ethics of new reproductive technologies as well as members of the public may have different views on whether the 14-day limit should be extended and genome editing applications to human embryos allowed. It provides reasons for a normative commitment to respecting these views and taking them into account when deciding how to regulate these technologies. Value pluralism, in other words, provides a non-

instrumental reason to shape regulatory strategies in ways that respect and reflect these conflicting views. Other than this meta-ethical and normative commitment, instrumental arguments pertaining to the importance of maintaining trust, ensuring the legitimacy of decisions on these matters, and the epistemic benefits of guarding against error provide reasons for considering people's views within institutional design.

When the 14-day limit was first enshrined in law, it was thought to be a solution that could best accommodate what were perceived to be the public's conflicting views on embryo research. These views might be different today, but if there continues to be disagreement on embryo research and on the 14-day limit then a compromise might still be the approach that best considers and respects the plurality of values co-existing in our societies. While compromise can serve this purpose, it does not settle the question of whose views should be included in democratic processes. To this end, I have presented and discussed an approach to regulate applications of genome editing technologies to early human embryos informed by the framework of deliberative democracy and by the idea of well-ordered science. Once again, such an approach could be defended both for instrumental and non-instrumental reasons.

## **2 Concluding Remarks: Past, Present, and Future**

The question of who should come into existence has received different answers depending on the historical, cultural, social, and political contexts in which it has been asked, and depending on the value system of reference of those asking it.

At the time of 20<sup>th</sup> century eugenics, the scholars, politicians, and activists who asked this question believed that people were not born equal and that some of them constituted a net cost to the overall functioning of society. These beliefs were often informed by misguided views on the mechanisms of heredity; by a positivistic faith in the science of heredity; by fears that unconstrained procreation would have dire effects on everyone else; as well as by nativist, racist beliefs (Lombardo 2018). Eugenacists' answers to the question of who should come into existence, and the ideas and policies that stemmed from these answers were often morally troubling



and led to discrimination, killings, reclusions, and other wrongs whose effects can still be witnessed.

Today, some of the authors, policy-makers, activists, politicians, ethics committee members, healthcare professionals, journalists, prospective parents, and other members of the public who ask the question of who should come into existence worry about the negative effects of new reproductive technologies while others celebrate their potential. They also reflect on how new reproductive technologies may change our lives and value-systems, and how these technologies should be developed and regulated to serve the public good. They answer the question of who should come into existence by employing different persuasive and argumentative strategies and a plurality of values and beliefs inform their views. Today's moral disagreement on who should come into existence and on how to balance the burdens and benefits of such decisions keeps debates on these questions going. It forces those who participate in them to consider (and reconsider) their own views; to recognise that different values and world-views coexist in our societies; and to avoid the risks of dogmatism and blindness denounced by Mill (1979/1859, Ch 2). Such disagreement serves as a reminder that different concerns and views may be informed by one's position in society, one's belonging to a certain socio-economic group, and influenced by one's communities of reference. What is important is to bear in mind that the ethical questions we ask, the policy solutions that we propose, and our conversations need to draw on "the full richness of humanity's moral imagination" (Jasanoff & Hurlbut 2018: 437): especially considering how past (and, debatably, present) forms of discrimination have contributed to the systematic exclusion of certain groups from these conversations.

What, then, of the future? The last part of this thesis represents an attempt to map, and contribute to some of the conversations that I believe should keep bioethicists busy in the future. Scientists will keep on developing new reproductive technologies and our scientific knowledge and technical possibilities will expand in the near and far future. Hence the debates on the ethical, social, and political questions raised by such knowledge and technical possibilities will have to continue. Despite this, my hope for the future is that in addition to these debates we will devote our ethical

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attention to questions raised by the far-reaching and cumulative effects of procreative decisions.

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Asking the question of who should come into existence, and learning from past and present attempts to answer this question helps us keep our ‘eyes on the prize’<sup>231</sup>. It helps us concentrate our attention and channel our efforts towards what we consider of value and what we believe to be worth discussing, arguing about, and going out into the streets for. This is the prize, which is worth all this and more. What each of us will consider worthy of the label of ‘prize’ may once again differ, but together we will find ways to live ethically on this planet and to reflect on procreation whilst trying to work towards inclusivity in freedom, and to justly distribute the burdens and benefits of our procreative decisions.

At least, I hope so.

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<sup>231</sup> I owe the inspiration for this expression to John Harris. During several conversations when I was conducting research for this thesis, Harris kept on asking me what ‘the prize’ of this research was for me and reminding me that when we write and conduct research, we must always ask this question of ourselves.

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# APPENDICES

## 1 Appendix 1

Cavaliere, G. (2018d). Looking into the shadow: The eugenics argument in debates on reproductive technologies and practices. *Monash Bioethics Review*, 36(1), doi: 10.1007/s40592-018-0086-x



# Looking into the shadow: the eugenics argument in debates on reproductive technologies and practices

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## Abstract

Eugenics is often referred to in debates on the ethics of reproductive technologies and practices, in relation to the creation of moral boundaries between acceptable and unacceptable technologies, and acceptable and unacceptable uses of these technologies. Historians have argued that twentieth century eugenics cannot be reduced to a uniform set of practices, and that no simple lessons can be drawn from this complex history. Some authors stress the similarities between past eugenics and present reproductive technologies and practices (what I define throughout the paper as ‘the continuity view’) in order to condemn the latter. Others focus on the differences between past and present practices (what I define throughout the paper as ‘the discontinuity view’) in order to defend contemporary reproductive technologies. In this paper, I explore the meanings of the word ‘eugenics’ and the relationship between its past and present uses in terms of contemporary debates on reproductive technologies and practices. I argue that moral disagreement about present technologies originate in divergent views of condemnable and justifiable features of the past.

**Keywords** Eugenics · Reproductive technologies · Coercion · Stigmatisation · Disability

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## 1 Introduction

New assisted reproductive technologies such as mitochondrial replacement techniques (MRTs), reproductive screening technologies such as pre-implantation genetic diagnosis (PGD), pre-natal diagnosis (PND) and non-invasive prenatal testing (NIPT), as well as gene editing technologies such as CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats) incite ethical controversies.<sup>1</sup> They do so because procreating and raising children, and influencing the type and number of people who will inhabit our planet in the future, touch upon people's core moral beliefs and values. Partly for this reason, assisted reproductive technologies and practices engender moral disagreement and give rise to many highly controversial debates in bioethics. Examples of the questions discussed within these debates include whether or not technologies will bring about better or worse states of affairs compared to the status quo; whether their introduction will cause increased injustice, discrimination, sexism, ableism and racism; or whether they will make our lives (or our children's lives) happier, healthier and/or longer. Some arguments focus on the consequences, and others concern the intrinsic goodness or wrongness of these technologies and their applications.

While the ethical questions discussed in these debates in academia, the media and other public fora are fairly diverse, one set of these questions has a common and recurrent feature: eugenics. This set of questions includes whether a given technology is eugenic, whether it might bring eugenics back, and whether this possibility is something to be feared or welcomed. What is referred to as the “shadow of eugenics” (Buchanan et al. 2001, p. 27)—namely the collective memory of condemned practices such as forced sterilisations as well as the condemned science of heredity, shared systems of belief, policies and ideas of different actors—continues to permeate today's ethical debates on reproductive technologies and practices. As I show in this paper, some authors stress elements of discontinuity between past eugenics and contemporary reproductive technologies and practices, while others focus on elements of continuity between past and present. Both groups agree on the wrongness of past eugenics, but they have different views on the relationship between past and present, and especially on the ethical standing of present technologies and practices. Authors who hold what I refer to as the “discontinuity view” between past and present defend reproductive technologies and practices, grounding some of their arguments in the differences between the latter technologies and the eugenic past; while those holding what I refer to as the “continuity view” condemn these technologies and practices, their arguments grounded in similarities with the past.

The content of the arguments underlying the discontinuity view varies slightly, but their form can be summarised as follows:

“Eugenics was intrinsically wrong because it entailed x, y, z; other things being equal, reproductive technologies and practices are not wrong because they lack x, y, z”.

<sup>1</sup> Throughout the paper, if I am not referring to a specific technology or practice, I refer to all of them collectively as ‘reproductive technologies or practices’.

Similarly, the content of the arguments of scholars who hold the continuity view varies slightly, but their form is homogeneous:

“Eugenics was intrinsically wrong because it entailed x, y, z; reproductive technologies and practices are likewise wrong because they similarly have elements of x, y, z”.

Considering that arguments drawing on the discontinuity and continuity between past and present are subsumed in the ethical assessments of reproductive technologies and practices, one would expect a knowledge of both the past and the present to play an important role in such assessments. In other words, considering that both arguments heavily rely on ‘x, y, z’, i.e. on problematic features of past eugenics, to ground their condemnations or absolutions of reproductive technologies, one would expect their assessments to be supported by sound and detailed historical analyses.<sup>2</sup> However, this is not entirely the case. As I show in this paper, what authors consider the capital sins of past eugenics vary greatly, and many of their arguments about both the past and the present are not based on in-depth historical analyses (Bashford 2010; Paul 1998). Past eugenics is assumed to be something despicable that ought not to be repeated, but those who participate in debates on the ethics of reproductive technologies and practices often fail to explicitly refer to what was wrong with eugenics and why.<sup>3</sup> Furthermore, these arguments rely on accounts of the history of eugenics often limited to the practices carried out during Nazism, and to racist and coercive dimensions of eugenics policies and practices (Bashford 2010). Why is this the case? One potential answer is that there is a division of “*cognitive labour*” among academics ([emphasis in original] Kitcher 2011, p. 193), and: “a group of investigators, addressing a common problem, pursues different approaches to that problem” (Kitcher 2011, p. 193). Those who participate in debates on the ethics of reproductive technologies and who employ the arguments outlined above are often philosophers, theologians, sociologists, biotechnologists and so forth; they are rarely historians.

Before delving into the work of historians of eugenics and their influence on debates on reproductive technologies and practices, it is necessary to give a short statement on the structure of the paper. In the next section, I present the work of historians of eugenics and discuss how they have tried to bring to light the multiplicity of practices, policies and actors that characterised twentieth century eugenics. Next, I focus on the meanings of the word ‘eugenics’ and present some of the definitions which are used in debates on reproductive technologies to describe this phenomenon. I identify different strategies to describe eugenics and criticise the use of definitions that presuppose its moral wrongness. I then turn to what I define as the discontinuity and continuity views of the relationship between past and present. I discuss both views and show that they rely on different assessments of what was wrong in the past and that these assessments of the past play an important role in

<sup>2</sup> In addition to being informed about these technologies’ and practices’ technical characteristics, their potential applications, safety, efficacy, etc.

<sup>3</sup> With notable exceptions. See for instance: Buchanan (2007), Buchanan et al. (2001), Camporesi (2014), Gyngell and Selgelid (2016), Selgelid (2000), Wikler (1999).

authors' assessments of the present. My hope is that reflecting on the meanings of 'eugenics', on the relationship between past and present, and on the roles and the understandings of eugenics will shed some light on its shadow and contribute to debates on the ethics of reproductive technologies and practices.

### 1.1 Where are historians when we need them?

In the comparison of reproductive technologies and practices to a historical phenomenon, eugenics, historians could help settle at least *some* of the questions that cause the moral disagreement among scholars participating in debates on their ethical standing, such as whether the similarities between past and present are so significant that the comparison is warranted. Many historians have indeed tried to make sense of the history of eugenics and to reconstruct it while taking into account its complexities, divergences and multifaceted aspects. It is therefore surprising that in debates on the ethics of reproductive technologies, the comparison with this past phenomenon is often made without reference to studies of the history of eugenics, and that the homogeneity of this past phenomenon is often taken as a given. For instance, Bennett (2014) calls Harris' and Savulescu's arguments in favour of using PGD to create the best possible child a "eugenic vision". Despite this, she fails to specify what she means by 'eugenic', to refer to the historical unfolding of this phenomenon and to its relationship with PGD and with the work of both Harris and Savulescu. Similarly, Savulescu and Kahane (2009), in their seminal work on procreative ethics and PGD, refer to eugenics in terms of "moral atrocities" and of "the collectivist, coercive and often racist projects of the twentieth century" and conclude that the procreative principles that they have discussed "bear little resemblance" with eugenics. Again, eugenics as a historical phenomenon is a point of reference devoid of its historical unfolding. As Koch (2004) argues:

[T]he witless reference to 'eugenics' with no further specification is empty and more often a function of our own projections and intentions than a reference to history. (Koch 2004, p. 329)

Historians and science and technology studies scholars have shown how eugenics, throughout history, cannot be easily reduced to a uniform set of practices and to a univocal ideology (Bashford 2010; Bashford and Levine 2010; Ekberg 2007; Kevles 1985; Koch 2006a; Meloni 2016; Lombardo 2008, 2011; Paul 1984, 1992). Eugenics encompassed a diverse set of practices that included not only race-based segregations and the institutionalisation and (at worst) the killing of the 'feeble-minded', but also the development of public health and sexual hygiene programmes aimed at improving environmental conditions (Gyngell and Selgelid 2016), education programmes aimed at spreading eugenic ideas; contests for the 'fittest' American family and campaigns for women's right to abortion and access to contraception (Roberts 1997). It encompassed a wide range of policies such as the Immigration Restriction Act in the US, sterilisation laws in the US, Scandinavian and other countries, but also the legalisation of abortion in some of these countries (with the exception of for instance Norway) (Koch 2006a). It involved a variety of actors belonging to different

political parties and embracing different ideologies (Kevles 1985; Meloni 2016; Paul 1984; Roberts 1997), from conservative defenders of the status quo to feminists campaigning for reproductive rights and from socialists and liberal democrats to racist right wingers. It was grounded in “epistemically pluralistic” theories of heredity, with both Lamarckian and Mendelian views influencing eugenic thinking (Gyngell and Selgelid 2016; Meloni 2016, p. 74; Schneider 1990), and both “soft” and “hard” theories of heredity justifying its principles (Meloni 2016, p. 65). It also involved the creation of different institutions such as the British Eugenics Society, the US Eugenics Record Office and the Mexican Eugenics Society. Contemporary historians (Adams 1990; Bashford 2010; Bashford and Levine 2010; Ekberg 2007; Kevles 1985; Koch 2006a; Lombardo 2008, 2011; Paul 1984, 1992) have set out not only to trace this history but also to show that eugenics was not confined geographically to Germany and North America and historically to the years immediately before, during and after World War II, but rather to a much more encompassing period of time and to diverse geographical areas: including Latin America, Central, Eastern and Northern Europe, and China. Differing views of the science of heredity (Gyngell and Selgelid 2016; Meloni 2016) and socio-political contexts (Roberts 1997) gave rise to a differing set of concerns, interventions and policies among geographical regions. For instance, as Roberts (1997) shows, in North America eugenicists and feminists (such as Margaret Sanger, who advocated for birth control measures) formed alliances as the former “gave the birth control movement a national mission and the authority of a reputable science” (Roberts 1997, p. 72), thereby inspiring policies in line with North America’s focus on controlling reproduction. Lamarckian and soft theories of heredity inspired eugenics programmes in Latin America and the ideas of British thinkers from the left (Gyngell and Selgelid 2016; Paul 1984, 2006), giving rise (in Latin America) to programmes aimed at “improving environmental conditions that influence transmissible (acquired) traits” (Gyngell and Selgelid 2016, p. 148).

Despite the differences among policies, actors, countries and periods of time, some of the features of twentieth century eugenics common across time, space and political affiliations tend to emerge in contemporary discourses on these technologies and practices. These shared features of eugenics<sup>4</sup> are best identified in eugenics as an ideology (i.e. a set of ideas and beliefs) rather than in eugenics as a practice (i.e. laws, institutions and eugenic education). Eugenics as a practice was a rather heterogeneous phenomenon, but it is possible to identify a core: one that it is shared over time, space and political affiliation.<sup>5</sup> This core was a concern with improving the quality of the population by preserving some human features considered

<sup>4</sup> For an interesting analysis of eugenic ideas throughout Western philosophical and political thought, see Häyry (2008).

<sup>5</sup> Concerning this, Meloni (2016) argues that “the varieties of eugenics in the first decades of the twentieth century were united less by direct politicization of a particular theory of heredity than by a *common ethos*, which crossed over the linguistic and aesthetic borders dividing eugenic approaches” (emphasis in original) Meloni 2016, p. 66). The author identifies four main features of this “common ethos”, namely: radical biologism, utopian social engineering, “unlimited empowerment of scientific experts”, and the primacy of the race over the individual (Meloni 2016, pp. 66–67).



beneficial for the collective and to avoid, or at least reduce, the transmission of negative features.<sup>6</sup> The etymological definition of eugenics and the definition formulated by Sir Francis Galton, the “father” of eugenics, capture these shared features. Etymologically, eugenics is composed of the Greek prefix ‘eu’ that translates as ‘good’ and the Greek word ‘genos’ that means ‘birth’ or ‘ancestry’. Galton’s original definition dates back to 1883, when he defined eugenics as:

*The science of improving stock*—not only by judicious mating, but whatever tends to give the more suitable races or strains of blood a better chance of prevailing over the less suitable than they otherwise would have had. ([emphasis added] Galton 1883)

These few features of eugenics as an ideology taken together represent the core of eugenics or, following Meloni (2016), the “common ethos” of eugenics, but it is still difficult to draw lessons on which to base ethical assessments of reproductive technologies and practices (Bashford 2010; Paul 1998). When critics and proponents of reproductive technologies and practices warn that we should be wary of “going back” to eugenics or that we should be very careful not to duplicate it, it is not always clear what they mean; as Paul (1998) puts it: “we’re warned against nothing in particular” (Paul 1998, p. 98).

Due to this complexity, and the emotional power that eugenics has, Wilkinson (2008), Camporesi (2014) and others working in the field of bioethics have suggested that reference to it ought to be abandoned, or at least significantly limited, in debates on reproductive technologies and practices. Their pleas, as well as contemporary efforts to distinguish between ‘good’ and ‘bad’ forms of eugenics, have not really changed current discourses on assisted reproduction as “the identification of a policy or practice as eugenic remains highly stigmatizing” (Paul 1998, p. 261) and references to eugenics in this context continue to abound.

So, historians are there and we need them. They have significantly helped to shed light on the history of eugenics and on the understanding of this phenomenon, on its complexity and multifaceted character. Depending on which aspects of this multifaceted history contemporary authors, policy-makers, journalists, activists and other members of the public look at, different lessons can be drawn and different strategies can be used to discuss, report, regulate, reject or defend reproductive technologies and practices. If eugenics is only depicted in terms of coercion or a quest for perfection (and assuming that both these practices are really ethically troubling), then what today’s technologies and practices need to avoid is to be driven by the latter and organised in terms of the former. If, instead, eugenics was really characterised by differing views of heredity, ideologies, objectives, policies and practices then its lessons are much less straightforwardly derived (Buchanan et al. 2001). Despite this, I would regard knowing a comprehensive account of the history of eugenics as an

<sup>6</sup> In this paper, I do not focus on or assess historical features of eugenics as my aim is to reflect on the relationship between past and present, and on how past eugenics is used in contemporary ethical debates. For detailed accounts of the history, see for instance: Adams (1990), Bashford and Levine (2010), Kevles (1985), Lombardo (2008, 2011).

ethical practice.<sup>7</sup> It is an ethical practice as on the one hand such knowledge can foster approaches, debates, interventions and policies that are not only mindful of what went wrong in the past, but also try to prevent (and perhaps redress) similar unfoldings. On the other, it can foster debates that are critical of and reflexive towards the social and political contexts in which they take shape and considerations of how both good and bad intentions can lead to undesirable states of affairs.<sup>8</sup>

What all the historical analyses have not managed to do is put to rest contemporary disagreement on what present technologies and practices count as eugenics and whether the similarity between past and present is a sufficient condition to settle the question of their ethical standing and value (Wilkinson and Garrard 2013). What *role* does the shadow of eugenics play within debates on reproductive technologies and practices? The reference to eugenics cuts across competing assessments of reproductive technologies and is used in different ways to create ethical boundaries between acceptable and unacceptable technologies, and their acceptable and unacceptable uses. Within these debates, recurrent questions are whether these technologies and practices amount to eugenics and/or whether they will lead us back to eugenics. However, if we aspire to move towards fruitful debates on the ethics of these technologies, I argue that our attention should be directed elsewhere. An alternative strategy to use in debates on the value and ethical standing of reproductive technologies is to look into the shadow of eugenics and uncover the relationship between past and present, how diverging interpretations of past practices inform our understanding of the present, and how they influence the contemporary disagreements concerning the ethics of reproductive technologies and practices. Looking into the shadow could, in other words, help those who participate in these debates to ask the right questions in order to collectively make progress both in the ethical assessment of these technologies and practices as well as in ethical debates on these technologies more generally.

Foucault, and Socrates before him, taught us that it is worth bearing in mind the importance of taxonomy and of reflecting on meanings as powerful analytical tools to interpret the complexities of reality. Looking into the meanings of eugenics is of interest as a conceptual tool to interpret the present. As Paul (1992) argued:

Eugenics is a word with nasty connotations but an indeterminate meaning. Indeed, *it often reveals more about its user's attitudes* than the policies, practices, intentions, or consequences labelled. ([emphasis added] Paul 1992, p. 665)

In the remainder of this paper, I will explore two questions: the role of the meanings and the uses of the word 'eugenics' in debates on reproductive technologies

<sup>7</sup> For an interesting discussion of the relationship between history and bioethics and of how these scholarships can be mutually beneficial, see Wilson (2013).

<sup>8</sup> Relatedly, Buchanan et al. (2001) concur that different accounts of the history have different implications for today's policy debates and that if today's genetics is "eugenics under a different name", then "we must achieve a clear understanding of the morality of both" (Buchanan et al. 2001, p. 40). See also Wikler (1999) and Gyngell and Selgelid (2016) on the lessons of eugenics.

and practices, and the role of assessments of the history of eugenics (and the lack thereof) in these debates. It is informed by an extensive review of publications that refer to eugenics to strengthen and ground arguments on the ethics of such technologies and practices.

## 2 What's in the name 'eugenics'?

In contemporary debates on the ethics of reproductive technologies and practices, the word 'eugenics' is defined in a multiplicity of ways. The disagreement regarding the meaning of 'eugenics' is not limited to what definition is the most appropriate and why, but rather it centres on "what counts as eugenics" (Wilkinson and Garrard 2013, p. 2), i.e. on which reproductive technologies and practices can be classified as eugenics, and whether this classification can settle the ethical questions that they raise. This section of the paper focuses on the role of the meanings, descriptions and definitions ascribed to eugenics in contemporary debates on reproductive technologies and practices.

One strategy to define the word 'eugenics' or to describe this phenomenon<sup>9</sup> within these debates would be to rely on a definition that is as descriptively accurate as possible, i.e. one that goes beyond the multiplicity of practices, ideologies and actors to capture the shared features of this multiplicity and that strives for neutrality in that it tries not to presuppose any explicit negative or implicit built-in value-judgment.<sup>10</sup> An example of such a definition of 'eugenics' would be: "the attempt to influence the genetic endowment of future generations".<sup>11</sup> Many of the authors who refer to eugenics in debates on the ethics of reproductive technologies adopt this strategy and rely on this type of definition of eugenics.<sup>12</sup> For example, Anomaly (2014)

<sup>9</sup> Whether the word 'eugenics' should be referred to at all is discussed in the following section.

I do not explicitly discuss the proposal of Agar (2008) and others who share his view of rehabilitating the term 'eugenics' by adding the adjective 'liberal'. While this use of the term 'eugenics' differs from the uses of many other authors, those who speak about "liberal eugenics" too have to decide which strategy among the ones described in this section they would adopt.

<sup>10</sup> A detailed discussion of the question of whether definitions can be entirely neutral, i.e. whether they can avoid *any* implicit or explicit value judgement is beyond the scope of this paper. I am personally sceptical with respect to the possibility of complete value-neutrality in definitions and descriptions of technologies and practices that are so fraught with emotive meanings, if only because definitions are formulated by "moral animals" (Wright 1994): human beings with values and moral beliefs. For the present purpose, it is sufficient to say that whilst complete neutrality might be unattainable (Lakoff 2004; Stevenson 1937), the degree to which this can be attempted varies greatly, and one could opt for a definition that is as descriptively accurate as possible.

<sup>11</sup> This sentence captures the core of different definitions found in the literature which rely on the strategy described above, but the exact terminology might vary from publication to publication.

<sup>12</sup> What I would consider a subset of this group is made by authors who rely on a definition that captures shared features of eugenics (its core) and that is hence descriptively accurate, but which employs the word 'improvement' to describe attempts to intervene in and influence the genetic endowment of future generations. For instance, Selgelid (2014) defines 'eugenics' "broadly" as: "a practice that aims to improve human lives by employing an understanding of heredity in the exertion of control over who gets born or who reproduces" (Selgelid 2014, p. 3) and Glover (2006) adopts the same strategy (see note below). Defining 'eugenics' in terms of improvement entails remaining true to Galton's original definition, which is arguably an instance of descriptive accuracy. Despite this, defining 'eugenics' in terms of

describes eugenics as: “any attempt to harness the power of reproduction to influence the genetic composition of future people” (Anomaly 2014, p. 179). Similarly, Glover (2006) argues that eugenics can be understood “broadly”<sup>13</sup> as “any decisions, including parental decisions, about what sort of child will be born” (Glover 2006, p. 28). As I discuss in the next section, most of the authors that adopt this strategy (and most authors in general) do condemn eugenics, but they are also broadly in favour of reproductive technologies.<sup>14</sup>

A second strategy adopted by those who refer to eugenics in debates on reproductive technologies and practices is to rely on a definition or description of it that incorporates background ethical assumptions on the (negative) ethical standing of eugenics. For instance, Garland-Thompson (2012) describes “eugenic logic” as aiming to “eliminate disability and, by extension, disabled people from the world” (Garland-Thompson 2012, p. 340). Authors who oppose the use of CRISPR for germline editing and of MRTs associate eugenics with these practices (Brokowski et al. 2015; Darnovsky 2013). Similarly, in authors who condemn human enhancement, eugenics becomes synonymous with enhancement (and equally condemned) and the antonym of treatment (Habermas 2003; Sandel 2004). Whether disability should be eliminated, or whether germline editing and human enhancement should be pursued, is a matter of contention in bioethics, as debates on the ethics of human enhancement,<sup>15</sup> on the ethics of screening technologies that allow to select against disability<sup>16</sup> and on the ethics of germline editing<sup>17</sup> show. My claim here is that these descriptions and definitions incorporate background ethical assumptions against germline editing, enhancement or against building a disability-free world and on the—related—ethical standing of eugenics. Hence, they opt for a different strategy to define and describe eugenics from the first group of authors described above.<sup>18</sup>

Therefore, even if authors tend to agree on the negative connotations of ‘eugenics’, they opt for different strategies to define this word. But which strategy should be preferred? Should we opt for descriptive accuracy or for a definition that conveys a message that expresses one’s own moral beliefs on the wrongness of eugenics? Or, again, should the word ‘eugenics’ be employed at all? As often, the answer to these questions depends on what one wants to achieve by using this word.

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Footnote 12 (continued)

*improving* the gene pool (or with its terminological sibling ‘producing “fine children”’, Harris 1993, p. 178) may be interpreted as sneaking in a positive connotation and a built-in value judgement and hence failing the ‘strive for descriptive accuracy and neutrality’ test. I am indebted to César Palacios-González for bringing this to my attention.

<sup>13</sup> According to Glover (2006), eugenics can be also understood “narrowly” as: “social policies aimed at improving the gene pool” (Glover 2006, p. 28).

<sup>14</sup> Other than the authors mentioned above, examples of authors in favour of new reproductive technologies that define eugenics in descriptively accurate terms are manifold. Just to mention a few of these authors: Agar (2008), Gyngell and Selgelid (2016), Robertson (2005).

<sup>15</sup> See for instance: Buchanan (2011), Harris (2007), Sandel (2004), Savulescu and Bostrom (2009).

<sup>16</sup> See for instance: Edwards (2004), Parens and Asch (2003), Shakespeare (2006).

<sup>17</sup> See for instance, Gyngell et al. (2016), Cavaliere (2018).

<sup>18</sup> I am thankful to one of the anonymous reviewers for raising important questions about this section and for pressing me to improve it.

## 2.1 Descriptive accuracy or conveying a message?

Many who refer to eugenics in debates on reproductive technologies either use a comparison with the past to show that such technologies are similar to eugenics and hence as morally problematic (the argument underlying the continuity view) or to show that these technologies are different from eugenics and hence not as morally problematic as eugenics was (the argument underlying the discontinuity view). In both types of arguments, the reference to eugenics is used to support one's position on the ethics of the reproductive technology or practice in question. It has, in other words, a normative role. Considering that both proponents and critics of reproductive technologies and practices agree on the negative connotations of eugenics, it may seem *prima facie* that it does not matter which definition they employ. They can say that eugenics is an attempt to improve the human gene pool or that it is an attempt to eliminate disabled people, and it would not matter for their arguments on contemporary technologies because that is where the moral disagreement lies. But words, metaphors and rhetoric matter greatly in these debates (O'Keefe et al. 2015; Ravitsky et al. 2015). As Blackburn (1998) argues: "words typically nudge people, with more or less subtlety, towards attitudes to the things they pick out" (Blackburn 1998, p. 15), and they can redirect people's interests (Stevenson 1937). Employing the word 'eugenics' and a certain definition of it has normative implications: as Wilkinson (2008) shows and as others argue (Camporesi 2014; Gillon 1998; Paul 1998), the *use* of the word 'eugenics' in contemporary debates on reproductive technologies has significant implications due to its emotive power and negative connotations.

Studies in moral psychology have provided evidence for how wording, context and order have *framing effects*,<sup>19</sup> namely they influence people's moral judgements on different matters (Haidt and Baron 1996; Haidt and Björklund 2007; Lakoff 2004; Petrinovich and O'Neill 1996; Sinnott-Armstrong 2007). A person's (moral) beliefs would be subjected to a word-type framing effect when "whether [or not] the person holds the belief depends on *which words are used to describe* what the belief is about" ([emphasis added] Sinnott-Armstrong 2007, p. 52) rather than on what the belief is actually about. So, a person's intuitions are subjected to framing effects if their moral beliefs regarding a given reproductive technology depend on the way the technology is described, on *which kind of words* are used to describe it rather than on the technology and its applications. Choosing one type of definition over another

<sup>19</sup> Word-framing effects have been studied most notably by Petrinovich and O'Neill (1996) and by Haidt and Björklund (2007). Petrinovich and O'Neill (1996) observed the effects on people's judgements on a given question being formulated in two different ways (one including the word 'kill' and the other including the word 'save') to describe two situations which would generate the same consequences. The consequences of the action entailed a certain number of people being killed and a certain number being saved in both situations, but participants were consistently much more likely to act when the word 'save' rather than when the word 'kill' was employed in the question. They judged the action more morally problematic (and hence they were not keen to act) when the word 'kill' appeared in the question. This is a typical example of a word-framing effect, one that works towards redirecting people's interests as in the case of eugenics and reproductive technologies and practices.



matters normatively because it can influence people's moral judgements concerning reproductive technologies and practices, and hence the decision to employ one type of definition or another is not per se neutral (Lakoff 2004).

Wilkinson (2008) argues that the word 'eugenics' should not be used in debates on the ethics of selective reproductive technologies due to its emotive power and negative connotations. According to this author, the word 'eugenics' has the potential to unleash negative emotions that can "circumvent or neutralise people's critical-rational faculties" (Wilkinson 2008, p. 470) and cloud their judgement about the reproductive technology or practice being discussed.<sup>20</sup> Hence the word 'eugenics' should not be brought up because it fails to respect the autonomy of those who engage with these debates<sup>21</sup> (Wilkinson 2008), because it is descriptively inaccurate and because it does not add anything in terms of conceptual clarity (Camporesi 2014; Gillon 1998). I am sympathetic to such analyses and certainly in favour of conceptual clarity and of avoiding misleading and factually wrong<sup>22</sup> references to historical events. 'Eugenics' is indeed used as the "*reductio ad Hitlerum*" described by Strauss (1953) whereby a person or a practice becomes guilty by virtue of their association with the Nazis (Strauss 1953). The comparison between reproductive technologies and historical eugenics is often used to condemn by association these technologies.

Despite this, it seems odd that the best strategy to protect people's rational capacities is to deliberately avoid the use of a word, even a heavily emotively-loaded word. There are different reasons why the word eugenics features in association with reproductive technologies: it may be that the user believes that these technologies are similar to eugenics or at least that they are comparable to it in meaningful ways; or it may be that the user is motivated by eugenics' persuasive power and its potential to elicit negative assessments of reproductive technologies. In the former case, what matters is whether the user is factually wrong or not; in the latter, it matters what rules of moral argumentation are set in debates on reproductive technologies and practices.

As the stakes are high (we are talking about the ethical assessment of reproductive technologies and practices), it is reasonable to state that one should be careful about how to use the word 'eugenics' and how one chooses to define it. Hence, I would suggest that, contrary to what Wilkinson (2008) and others argue, we should aim to adopt a reflective approach to the use of the word eugenics rather than to make it taboo. We should aim for conceptual clarity, for definitions that are as

<sup>20</sup> Wilkinson (2008) discusses this phenomenon in the context of PGD.

<sup>21</sup> According to Wilkinson (2008), the word 'eugenics' should be avoided regardless of one's own moral beliefs on reproductive technologies and practices as "there are some ways of communicating that, without lying or misleading, fail to respect people's autonomy: methods of communication that circumvent or neutralise people's critical-rational faculties" (Wilkinson 2008, p. 470). Following this view, which Wilkinson considers "non-partisan" and defines as "the Autonomy argument" against using the word 'eugenics', both those in favour of and against reproductive technologies have an interest in not referring to the word 'eugenics' as both camps should aim for a "rational" debate.

<sup>22</sup> With the term 'factually wrong', I mean references to the past that do not describe documented events of the past or that deny that certain documented events have taken place.

descriptively accurate as possible, that fairly represent what eugenics encompassed, and that are informed by the work of historians of eugenics. A description-oriented definition of ‘eugenics’ would allow us to start with a common ground to discuss both the history of eugenics and the ethics of reproductive technologies.

There are different reasons why those who participate in debates on the ethics of reproductive technologies should, where possible, avoid definitions of ‘eugenics’ which are fraught with negative connotations and that conflate descriptive and evaluative elements. These definitions serve the normative goal of critics of reproductive technologies (i.e. elicit negative judgements of these technologies), but do not improve the ethical debate insofar as they turn the attention to whether these technologies are eugenics rather than on relevant moral aspects of these technologies. They pre-determine the moral questions and hence shape the debate by deciding beforehand which aspects should be given attention and which are irrelevant (Jasanoff et al. 2015). They pre-determine what ethical questions should be discussed and what direction the ethical debate should take, thereby excluding views that do not fit within the pre-established framework. They add ethical complexity to already complex questions, and they do not provide those participating in the debate with a way to make sense of this complexity. Regardless of one’s normative goal, then, intellectual honesty would call for definitions, meanings and uses of the word ‘eugenics’ which are as descriptively accurate as possible. Only in this way can we really assess whether the comparison with past and present is warranted and make steps forward in the ethical debate on reproductive technologies.

### 3 The discontinuity and continuity views

Let me take a moment to recall the form taken by two commonly used arguments within debates on the ethics of reproductive technologies and practices which involve references to eugenics. The first set of arguments that stress the discontinuity between past and present goes something like this:

1. x, y and z are morally wrong acts;
2. eugenic practices entailed x, y and z;
- ∴ old eugenic practices were morally wrong.
3. a (a reproductive technology or practice) does not entail carrying out x, y and z;
- ∴ other things being equal, a is not morally wrong.

The opposing set of arguments, which stress elements of continuity between past and present, runs something like this:

1. x, y and z are morally wrong acts;
2. eugenic practices entail x, y and z;
- ∴ eugenic practices are morally wrong.
3. a (a reproductive technology or practice) entails x, y and z;
- ∴ a is morally wrong.

Throughout the rest of the paper, I refer to these two views as the discontinuity view and the continuity view of past and present. My argument is that the understanding of the history of eugenics and the features of the history upon which one focuses are deeply interlinked with the claims that one makes about the ethics of reproductive technologies.

### 3.1 The discontinuity view

Those who hold the discontinuity view condemn characteristics of eugenics concerning its scientific foundations. More specifically, they hold that eugenics was informed by a limited knowledge of the science of heredity (Epstein 2003; Glover 2006), that it did not meet appropriate ethical and scientific standards of research (Appel 2012; Tong 2013), and that it mistakenly relied on the belief that social, behavioural and ethnic features could be flattened and reduced to mere biological dimensions (Buchanan et al. 2001; Scott 2006). A second problematic feature of eugenics is identified in its underlying racist and discriminatory beliefs, and in the policies that these beliefs inspired (Agar 2008; Buchanan et al. 2001; Robertson 2005; Savulescu and Kahane 2009; Scott 2006). The authors defending this view largely focus their attention on North American immigration policies designed to restrict incomers from certain ethnic groups (i.e. Southern and Eastern Europe), on American sterilisation policies that targeted people with physical and mental disabilities and members of lower socio-economical classes (Appel 2012; Crossley and Shepherd 2003), and on Nazi eugenics aimed at creating a “master race” through the elimination of people with disabilities (Blackford 2005; Glover 2006; Walker 2010).

In addition to bad science and discriminatory beliefs, in debates on reproductive technologies and practices, coercion becomes the capital sin of past eugenics<sup>23</sup> (Agar 2008; Bruni et al. 2012; Caplan et al. 1999; Crossley and Shepherd 2003; Glover 2006; Robertson 2005; Santosuosso et al. 2007; Savulescu and Kahane 2009). While agreeing that coercion was one of the most problematic elements of eugenics, authors discussing this feature focus on slightly different features of it: some criticise state interference in the realm of reproduction and the denial of what today is defined as “procreative liberty”<sup>24</sup> (Robertson 2005). Others mainly address the question of exercising control over biological features of the population (Bouffard et al. 2009; Dolgin 2004), whereas another group sees in coercion a denial of the respect for individuals’ bodily integrity (Appel 2012; Santosuosso et al. 2007). A final reason why eugenics is perceived as despicable is that its policies and aims were oriented towards the improvement of the wellbeing of the population rather than the good of the individuals (Fenton 2006; Glover 2006; Robertson 2005; Savulescu 2005; Scott 2006). In all these references to the past, despite some internal differences concerning the most contemptible elements of eugenics, old eugenics

<sup>23</sup> This is also shown by the number of publications which address the question of coercion. In spite of this, most of the authors do not define what they mean by coercion and which features make eugenic policies and practices coercive.

<sup>24</sup> Or, alternatively: “reproductive freedom” (Brock 2005; Harris 1992; Cavaliere and Harris 2018).



is unanimously condemned. What varies is the weight that should be assigned to ‘x, y, z’, i.e. to each of the features of eugenics on which scholars participating in debates on the ethics of reproductive technologies focus. The discontinuity view underlines the idea that if reproductive technologies and practices do not entail ‘x, y, z’, namely coercion, bad science, discriminatory beliefs and a precedence of population-concerns over individual-concerns, *then* they are not ethically troubling in the same way as eugenics.

Authors relying on the discontinuity view to support their disanalogy between the past and present argument make slightly different claims about the present and about the relationship between past and present. For instance, some argue that past eugenics and reproductive technologies do not share any significant feature (Bourne et al. 2012; Savulescu and Kahane 2009). These authors argue that reproductive technologies are guided by values and inspired by moral beliefs that have nothing to do with those of eugenics: while eugenics was discriminatory and exclusionist, reproductive technologies are value-neutral with respect to race, gender and class, and oriented towards the welfare of the future child or designed to enhance autonomous decision-making (Glover 2006; Harris 2007; Savulescu and Kahane 2009; Robertson 2005). In their accounts, past and present differ in terms of both the underpinning values and the means employed: while eugenics was coercive, violent, and entailed forced sterilisations and mass killings, today’s reproductive technologies are freely chosen, do not entail gruesome methods and are available to those who wish to use them (Appel 2012; Bourne et al. 2012; Robertson 2005; Savulescu and Kahane 2009).

Other authors allow that although these technologies share features with past eugenics, they are still free of the characteristics that made eugenics morally wrong (Agar 2008; Camporesi 2014; Fenton 2006; Harris 1993; Scott 2006; Wilkinson 2010). For instance, Wilkinson (2010) reflects on the question of whether “the very idea of ‘genetic improvement’ is a mistake” (Wilkinson 2010, p. 159) and concludes that the answer to that question, once we add some qualifications (which he offers in his book), is negative:

There have been many versions of ‘eugenics’ that have incorporated dangerously flawed ideological and pseudo-scientific beliefs, *such as Nazi racial ‘science’*. However, there is no need to assume that all attempts to improve the ‘gene pool’ will be similarly flawed [...]. So perhaps (for example) improving the gene pool in ways that improve future public health would be morally acceptable (and even desirable) ([emphasis added] Wilkinson 2010, p. 166)

Similarly, Harris (1993), in addressing the question of whether gene therapy should be considered a form of eugenics, argues that if one relies on an understanding of eugenics akin to the understanding that its father, Francis Galton, had, then the answer is positive. Eugenics and gene therapy have a common aim: they both seek to produce “fine children” (Harris 1993), an aim that, in the eyes of the author,

is considered worthwhile. This aim is worth pursuing both in the case of attempting to “remove or repair dysfunction” and in the case of “measures designed to enhance function”<sup>25</sup> (Harris 1993). These authors (and other sharing their view such as Agar 2008) rely on a broader understanding of eugenics as the attempt to improve the gene pool of the population and argue that what was problematic in the past was *how* eugenicists tried to achieve human improvement, i.e. the relying on coercive and violent measures, rather than on the aim of eugenics and its underpinning values per se.

### 3.2 The continuity view

The authors who defend the continuity view broadly agree with those defending the discontinuity view with respects to the condemnable features of eugenics. For instance, some scholars criticise its faulty scientific foundations and the quest for singling out biological components of social characteristics (Jeffreys 2012); others focus on the coercive character of eugenics’ policies and practices (Epstein 2003), their incorporation into the political agenda (Hampton 2005; Roberts 2009), their violation of bodily integrity and of reproductive freedom (Epstein 2003; Roberts 1997). Despite the similarities between those defending the discontinuity and the continuity view in terms of the condemned features of eugenics, the degree to which these features are considered problematic and the moral weight given to each feature differ substantially. Contrary to those who defend the discontinuity view, most of the authors defending the continuity view do not see in coercion and state-driven practices the capital sins of eugenics. They instead focus on eugenics’ discriminatory attitudes, on its morally wrong underpinning values, on the policies that were designed following these values, and on the effects on minorities and vulnerable groups of these attitudes, values and policies (Garland-Thomson 2012; Hampton 2005; MacKellar and Bechtel 2014; Roberts 1997, 2009; Rosen 2003; Sparrow 2011a). They also stress eugenics’ ‘unhealthy’ preoccupation with perfection (Bashford 2010) and argue that eugenic practices of the past were ultimately driven by the purpose of perfecting the population. This aim is considered problematic not because—as the defenders of the discontinuity view would argue—their efforts were directed at the population rather than at the individual, but because of the immorality of the aim itself (MacKellar and Bechtel 2014; Rosen 2003; Sandel 2004).

Commentators agree on the wrongness of most practices within twentieth century eugenics, on the aberrant means used to pursue its aims and on the need to avoid repeating these mistakes, but they draw different lessons from these analyses, and they develop competing assessments of contemporary reproductive technologies and practices. The reason for this, I argue, is that their views diverge on the underpinning

<sup>25</sup> Harris here relies on a critique of the existence of significant moral differences between therapy and enhancement. I will not enter in this debate here, but Harris, among others, does so throughout his work (1992 and 2010).

values of eugenics (such as the desirability of influencing the genetic endowment of future generations) and to the weight that is given to each condemned feature of twentieth century eugenics. The moral disagreement on the present has roots in a disagreement about the past,<sup>26</sup> and past and present are profoundly interlinked in these accounts.

Authors supporting the continuity view present a number of reasons to draw attention to the meaningful similarities between contemporary technologies and practices, and features of twentieth century eugenics. For instance, some stress that the (cumulative) effects of these practices match some of the effects sought by eugenicists or some of the effects eugenic policies sought to engender. Screening technologies such as PGD and PND, but also new reproductive technologies such as MRTs, will contribute to a decrease in the number of disabled people and to members of ethnic minorities (Hampton 2005; Garland-Thomson 2012; de Melo-Martín 2016; Roberts 2009). This decrease is considered by these commentators to be not only ethically troubling in itself, but also for consequentialist reasons, i.e. for the effects that it will have on these groups. The fear is that members of certain ethnic groups (Roberts 1997, 2015; Russell 2010), women (de Melo-Martín 2016; Epstein 2003) and disabled people (Garland-Thomson 2012) will be increasingly stigmatised, as they were in the past, and publicly funded services available to them will be reduced (Garland-Thomson 2012; Scully 2008; Sparrow 2008, 2011b).

While authors defending the continuity view do not see in coercion one of the chief wrongs of eugenics, they still condemn it and argue that some elements of coercion survive in contemporary reproductive technologies and practices. Unlike supporters of the discontinuity view, these authors stress that the alleged diminished intervention of the state in matters of procreation is either a misrepresentation of the present situation or a sign that coercion is understood in an unduly narrow sense. For instance, Sparrow (2008) argues that the fact that certain screening technologies are “made available” signals the continuity of state interventions in matters of procreation. Not only that, but according to other critics of reproductive technologies and practices that refer to eugenics, coercion is an element of today’s technologies and practices even if the state does not have an active role in promoting them (Mehlman 2011; Mittra 2007; Sparrow 2011b). Following these authors, other than from direct state interventions, coercion may result from the pressure to use reproductive and screening technologies exercised by healthcare professionals (Ekberg 2007; Koch 2006b), scientists (Darnovsky 2004; Ekberg 2007) and bioethicists (Koch 2006b). Other than coercion, what troubles defenders of the continuity view about eugenics is the quest for perfection that it entailed. In their view, this quest is embodied by reproductive technologies and practices (Sandel 2004).

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<sup>26</sup> As argued above, the past must be known in all its nuances and complexities in order to assess it from an ethical point of view and for it to be of any interest in present debates.

## 4 Learning and moving forward

I started this paper by arguing that historians have reconstructed the unfolding of eugenics and brought to light the multiplicity of themes, policies, actors and values which it encompassed. Learning from history in order not to repeat the mistakes of the past is a noble, and some would argue a necessary, endeavour. But to learn from history, history must be known. Partial or inexistent historical accounts make it extremely difficult to learn from the past and, as Bashford (2010) puts it:

Selective understandings of the history of eugenics may seriously mislead contemporary efforts to regulate reproductive and genetic technologies, and be a questionable basis for policy decisions. (Bashford 2010)

As I showed in the previous sections, despite unanimously condemning eugenics, defenders of the discontinuity and continuity views focus their attention on slightly different ethically troubling features of the past. While defenders of the discontinuity view see coercion and population-wide eugenic policies and practices as the most problematic feature of twentieth century eugenics, defenders of the continuity view see the callous attitudes towards disabled people and other minorities, and the drive towards improving the gene pool of the population, as the most despicable feature of eugenics. These differing ethical assessments of the past are linked with differing ethical assessments of the present: defenders of the discontinuity view stress how reproductive technologies and practices both promote and protect reproductive freedom and individual welfare (as opposed to population-wide approaches) and individual autonomy (as opposed to coercion). They see in the promotion and protection of these values the most salient characteristics of reproductive technologies and practices, and the reasons why they should be welcomed. On the contrary, defenders of the continuity view stress how reproductive technologies and practices both embody and play a role in the persistence of the drive towards perfecting the population and of the discriminatory attitudes towards women, disabled and black people, and the reasons why they should be condemned. They see in this condemnation and problematisation of these technologies and practices a means to promote different values. These differing ethical assessments of the past can also explain why proponents of the discontinuity view often dismiss concerns about the present expressed by those who support the continuity view. They dismiss them as signals of conservative attitudes towards new reproductive technologies and practices and of a poor understanding of today's effects and uses of these technologies and practices. However, in reality, the two groups condemn and justify different features of the past and of the present.

Historians and critical theorists have warned of the risk of focusing excessively on the coercive character of eugenics whilst ignoring the patterns of coercion and discrimination present in reproductive technologies and practices (Bashford 2010; Ekberg 2007; Roberts 1997). On the one hand, eugenicists advocated voluntary forms of eugenics; on the other, social pressure, discriminatory attitudes and barriers to fully exercise and to have respected one's reproductive freedom may be (in different ways) features of today's reproductive technologies too (Bashford 2010;

Koch 2006a; Paul 1992). The discontinuity view's underlying arguments draw a line between historical eugenics as coercive and reproductive technologies as freely chosen by autonomous individuals, but the reality is much more blurred than advocates of such technologies make it out to be. At the same time, authors focusing on the callous attitudes towards disabled people, women and ethnic minorities, and on persisting biases and forms of discrimination enacted within and by reproductive technologies and practices may risk overlooking significant differences from the past in terms of the political and social context in which reproductive technologies and practices are developed. While it is undoubtedly true that despicable attitudes still exist and that they should be resisted, efforts and steps towards fostering respect for these groups, to guarantee them public assistance and to develop means for greater integration, are being made. Additionally, empirical data have shown that parents who make use of reproductive technologies are not driven by a quest towards perfection or by discriminatory beliefs (Franklin and Roberts 2006; Kerr 2004).

Once history—in all its complexities, nuances, peculiarities—is known, we can learn from it. We can start with a common ground that avoids misleading assessments and misleading conclusions. Despite this, such knowledge about history cannot solve the moral disagreement concerning what underpinning values are worth pursuing and what others are worth dismissing. It cannot answer, in other words, the question of which aims and values reproductive technologies and practices should serve. History can tell us that coercion was not the only nor the most distinctive feature of eugenics, but it cannot tell us whether trying to improve the gene pool of the population and trying to increase the number of babies born without disabilities are worthy aims (as most defenders of reproductive technologies argue). Similarly, it can tell us about eugenic policies and how those policies contributed to an increased stigmatisation of disabled people and of the perceived need to wipe them out, but what it cannot tell us is whether allowing gene editing technologies will lead prospective parents to select blond blue-eyed babies and whether this is something that should be opposed.

For these reasons, while it is important to learn *about* the history of eugenics and learn *from* the history of eugenics, this is probably all that eugenics should contribute to contemporary debates on reproductive technologies. Mainly focusing on eugenics and on analogies/disanalogs between past and present risk jeopardising contemporary debates on the ethics of reproductive technologies and shifting the focus away from relevant questions about the value of reproductive technologies and practices.

## 5 Conclusions: looking into the shadow

In this paper, I have discussed how the word 'eugenics' and the history of eugenics are used in debates on the ethics of reproductive technologies and practices. I have showed that some commentators employ definitions of 'eugenics' which are descriptively accurate while others opt for definitions which immediately bring to the fore the negative connotations of this phenomenon. I have argued that, when possible, the former type of definition should be preferred over the latter. I then moved on



from a discussion of the uses of the word to the uses of the history of eugenics and showed how authors who focus on certain problematic characteristics of the past tend to have views on contemporary reproductive technologies and practices that are symmetric with, and a response to, these characteristics.

The shadow of eugenics extends to contemporary reproductive technologies and practices and it is a legacy that will probably be hard to eradicate, and it might not even be desirable to do so. Scholars who participate in debates on these technologies should learn about the historical unfolding of eugenics in order to avoid repeating the same mistakes that were committed in the past.

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## 2 Appendix 2

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# A Path Through the (Moral) Morass

## Genome Editing, Reproduction and Broad Conversations<sup>1</sup>

Giulia Cavaliere

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### Keywords

Assisted Reproduction, Deliberative Democracy, Moral Judgment, Pluralism, Safety

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### Abstract

In this chapter, I discuss the possibility of using genome editing technologies in the context of assisted reproduction. I present the most prominent arguments in favour of and against this use of genome editing technologies, and explore two strategies used in bioethics in the event of moral disagreement to analyse the questions at hand and to develop morally sound policies. These strategies are: the clarification of the facts regarding a new technology and the formulation of the best philosophical argument. I contend that both approaches are theoretically flawed and might result in states of affairs that fail to promote peoples' well-being. I then argue that we should focus instead on finding at least some common ground in order to move forward in the debate on genome editing, building a regulatory framework that lightens "the burden of human existence" (Harris 2016), whilst still accommodating opposing views as much as possible. Furthermore, I argue that insights from moral psychology and democratic governance can assist us in these challenges.

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## 1 Genetic Technologies and (Moral) Disagreement

New reproductive technologies and screening technologies allow couples who are at risk of transmitting genetic diseases to their offspring to reduce the risk of transmission while still being able to have genetically related (or partially genetically related) offspring. Most of these technologies and their applications are controversial. There is no consensus regarding the legitimacy of their use and whether or not they are a morally acceptable means in the pursuit of parenthood projects. Some people oppose pre-natal and pre-implantation screening technologies because of their discriminatory nature and because they express – or strengthen – negative attitudes towards people with disabilities (Parens et al. 2003). Others contest that these technologies could bring about increased inequality as well as sexist and racist attitudes (Roberts 1999). Others criticise them for violating human dignity and for tampering with human nature (Kass 1997), while still others are more concerned with the reinforcement of certain beliefs about the importance of genetic parenthood and the traditional family (de Melo-Martín 2017a). If there were agreement regarding these criticisms, bioethicists would be out of a job (together with the scientists developing them, the healthcare professionals working in the fertility clinics, and the policy makers regulating their use).

Fortunately (I am a bioethicist and I do not want to be out of a job), these technologies are also welcomed by many, since they allow people to pursue their preferred life plans, to have children that are genetically related to them, and who are healthier than they otherwise would have been. They, as Harris (2016) puts it, help “lighten the burden of human existence” (Harris 2016, 16). In this chapter, I focus on genome editing technologies and on their applications, in the context of assisted reproduction, for the correction of genetic abnormalities in embryos created with in vitro fertilization (IVF). I discuss this possibility, presenting some insights from the literature on moral psychology which can be considered a starting point for a debate on the challenges of institutional design.

Gene editing technologies have been around for over a decade now (Nuffield Council on Bioethics 2016). Despite this fact, one new gene editing technique in particular sparked a heated debate early in 2015, and to date, the debate has yet to be settled. Calls for a moratorium on the use of this particular technique as well as for international bans and joint efforts to prevent its applications in the clinic abound (Baylis 2017a and 2017b; Baltimore et al. 2015; Lanphier and Urnov 2015; UNESCO IBC 2017). The technique in question is CRISPR (Clustered Regularly Interspaced Short Palindromic Repeat), an RNA-guided tool that makes use of a naturally occurring defence mechanism employed by bacteria to avoid harmful infections caused by pathogenic organisms (e.g. viruses). The RNA tool (CRISPR)

functions as a guide for other systems (Cas9, CPF1 and others) to target specific parts of the genome, which are subsequently cut by the Cas proteins. These cut strands can be exploited to modify the nucleotide sequence of DNA and to insert DNA sequences at the cut site. The application of this technique to human embryos and human gametes (i. e., oocytes and sperm cells) has been widely criticised for a number of reasons, but chiefly for its potential to introduce inheritable changes in the human genome. The question of consensus has catalysed the attention of many scientists and ethicists and has transformed CRISPR into one of the most discussed technologies of the past years (Brokowski et al. 2015; Lander 2015; Lanphier and Urnov 2015). The technique's precision, effectiveness and relatively limited cost, together with its potential to edit the human germline in a targeted manner, which elevates it above many other genome editing technologies, have led ethicists, scientists, reporters and members of the public to call for international solutions to what is perceived to be an international challenge (Baylis 2017a and 2017b; The National Academies 2015).

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## 2 Broadening the Conversation

One of the proponents of these international solutions and broad conversations is Baylis (2017a and 2017b), who writes:

“Why struggle? Because although all humans have a common interest in the human genome, much work is needed to identify other common interests that might rightfully guide policy deliberations. Hence, there is merit in [...] embracing the challenge of seeking broad societal consensus on this ethically controversial issue.” (Baylis 2017b, 3)

Elsewhere, she continues defending the view that citizens should work towards broad societal consensus, because “[w]e are talking about nothing less than the future of the human species. No decisions about the modification of the germline should be made without broad societal consultation” (Baylis 2017a). Similarly, the statement produced after the International Summit on Human Gene Editing in December 2015 states that: “It would be irresponsible to proceed with any clinical use of germline editing unless and until [...] there is broad societal consensus about the appropriateness of the proposed application.” (National Academies 2015)

The problem with international and broad solutions is that we, members of *Homo sapiens*, often disagree. We disagree about everything: from climate change to national health services, from redistribution of income and wealth to genetically modified organisms, from vaccinations to sustainable diets. Our disagreements

span from the evaluation of scientific methods to ethics and policy. They occur between and within countries, depending on personal and collective values, beliefs and practices, and – importantly – political and cultural frames (Jasanoff 2011). We tend to see the world through “different moral lenses” when it comes to values we hold dear (Greene 2014, 68).

In the face of all these disagreements, we can adopt different strategies, including throwing in the towel and not attempting to build such broad social consensus, or forcing the view held by the majority on the minority. Broad societal consensus might be unachievable and perhaps even undesirable. It may be unachievable due to our differing moral worldviews and our tribal tendencies to defend them (Greene 2014; Haidt 2012). It may also be undesirable inasmuch as it requires those participating in the debate on the ethics of genome editing to relinquish at least some of these moral views, or to restrict them to the private sphere and not bring them to the fore/um. It requires doing ethics, not inside the cave and among philosophers and ethics experts, but in the public square, where different moral views and “competing rationalities” coexist (Häyry 2010, 48). This is what commitment to a deliberative conception of democracy would encourage us to do (Cohen 2003; Gutmann et al. 2009). It would encourage us to engage in a process of public reasoning, where we collectively discuss contrasting moral views and engage in “visions of progress that are collectively defined, drawing on the full richness of democratic imagination” (Jasanoff et al. 2015). As we move from bioethics journals to institutional design and public policy, we need to be able to create an inclusive space for discussion of the ethical, political and social challenges raised by genome editing. We need to be able to develop policies that take account of these challenges and the competing moral views and values that underpin them.

For this reason, I side with Baylis’ general intuition and with her plea for broad conversations on genome editing.<sup>2</sup> My view on the importance of an inclusive dialogue is motivated by a commitment to a deliberative understanding of democratic decision making, but also, as Peter Mills (2017) puts it, because we are in the field of “geo-ethics”, where what matters are the “interactions of formal institutions, organisations and polities that recognise the potential for the spatiotemporal diffusion of genome editing technologies across political geographies and legal jurisdictions” (Mills 2017, 69). It is within and between such diverse and broad

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2 I am not convinced by Baylis’ idea of “broad societal consensus”. I see the rhetorical appeal of such a proposal, but I think that aiming for “broad conversations” and trying to resolve, even partially, the disagreement is a) more feasible and b) more desirable. My argument then hinges more on the idea of “partially overcoming the disagreement”, and trying to have “broad conversations” (i.e. as inclusive as possible), than on Baylis’ idea of “broad societal consensus”.

contexts, within and between “different social and cultural realities”, that these technologies will be in play (Mills 2017).

What then should we do with genome editing? Should we take such competing moral views into account? Should we take all of them into consideration, or are there some views which should not be accepted in the public arena? Despite people’s tendency to favour the moral views that resonate with their own and to discard opposing views as flawed, immoral, unacceptable etc., when it comes to developing policies, there are very good reasons to try to find certain overlaps among differing “moral tribes” (Greene 2014). I return to these questions (and to a tentative response to them) in section 3. Before that, I briefly explain how genome editing could be used in the context of assisted reproduction and then delineate some of the arguments put forward against and in favour of this possibility.

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### **3 Reproductive Options and Genome Editing as a New Possibility**

Couples who do not rely on assisted reproduction, and who wish to reduce the risk of transmitting a genetic mutation to their offspring, could refrain from having genetically related children and turn to adoption.<sup>3</sup> Alternatively, prospective parents can rely on reproductive technologies, such as IVF with gamete donations (third-party reproduction), or screening technologies, such as pre-implantation genetic diagnosis (PGD), to decrease the risk of having children with the genetic mutation they carry. In some cases, PGD is not an option as none of the embryos created through IVF is free from the undesirable genetic mutation (Vassena et al. 2016). For instance, when one of the prospective parents is homozygous for a dominant genetic disorder, the risk of transmission to offspring is as high as 100%, and hence no mutation-free embryos can be obtained. When prospective parents are both heterozygous for a dominant genetic disorder, the risk of transmission is as high as 75%, making the chances of finding mutation-free embryos significantly low. Another case where PGD is not effective is when both parents are homozygous for a recessive genetic disorder (the risk of transmission to offspring is as high as 100%), meaning that they both carry two variants of the disease-causing gene

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3 I do not discuss this option in this chapter. Rather, I focus on the available options granted by existing and new assisted reproductive technologies. For a discussion of adoption, and why it is a morally preferable alternative to assisted reproduction, see for instance de Melo-Martín (2017a) and Rulli (2016).



(Nuffield Council on Bioethics 2016; Vassena et al. 2016). In such cases, genome editing could be employed directly on the embryos created with IVF to “correct” mutations which potentially lead to monogenic diseases, and to correct mitochondrial DNA mutations which lead to mitochondrial DNA diseases (Vassena et al. 2016).<sup>4</sup> Using genome editing on early embryos could give to prospective parents, who are at risk of transmitting genetic mutations to their offspring, a chance at having children who are genetically related to them, while decreasing the risk of transmitting the parents’ genetic mutations.<sup>5</sup>

### 3.1 Genome Editing: Proponents and Critics

Research on human embryos with CRISPR technology is still in an early stage and only a few experiments have been carried out thus far (Vassena et al. 2016). Despite this, the possibility of allowing clinical research has been discussed recently (Chan et al. 2015; Gyngell et al. 2016; The National Academies of Sciences, Engineering and Medicine 2017; Reyes and Lanner 2017; Vassena et al. 2016). Critics advance two related, precautionary reasons against clinical applications of genome editing on human embryos or gamete cells: that these applications would lead to germline modifications and that assessing the safety of these applications would be either problematic or impossible. Those who worry about germline modifications view them akin to an (ethical and biological) “line that should not be crossed” (Collins 2015; UNESCO IBC 2017).<sup>6</sup> The worry about germline modifications expresses two underlying types of concern: deontological concerns about the intrinsic wrongness of introducing inheritable changes in the human genome, and consequentialist concerns about unforeseen effects for future generations, technology’s running astray and the possible resurgence of eugenics (Lanphier and Urnov 2015; MacKellar 2017; Pollack 2015).

The first type of concern, which I refer to as “deontological”, implies a principled position against germline modifications, regardless of the morality of the outcomes

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4 Currently, the United Kingdom is the only country where mitochondrial DNA replacement techniques are allowed and regulated. Such techniques represent the only existing method for couples in which one member is affected by a mitochondrial condition to have genetically related children.

5 I do not discuss alternative forms of procreation, that do not entail genetic parenthood, in this chapter. I discuss the ethics of using new technologies to have genetically related, healthy babies and the broader societal implications of such decisions in Cavaliere 2017a.

6 For a discussion of this claim, see: Camporesi and Cavaliere 2016.



of such practices.<sup>7</sup> For instance, the 2017 statement of the UNESCO International Bioethics Committee (IBC) reads:

“Interventions on the human genome should be admitted only for preventive, diagnostic or therapeutic reasons and without enacting modifications for descendants. The alternative would jeopardize the inherent and therefore equal dignity of all human beings and renew eugenics.” (UNESCO IBC 2017)

Sometimes this principled objection echoes concerns regarding the intrinsic and inviolable value of human dignity and of what is “naturally” produced (Kass 1997; Sandel 2009), as opposed to what is technically designed.

The second type of concern, which I defined as “consequentialist” due to its focus on the state of affairs possibly effected by genome editing, encompasses objections related principally to the unforeseen effects of modifying the human germline, and the impossibility of thoroughly assessing the safety of these technologies (Baylis 2017b; Lanphier and Urnov 2015). At the current stage, safety is indeed an issue, and the efficiency of genome editing on embryos is still low, with mosaicism in edited embryos (i.e., edited embryos showed a mixture of edited and unedited cells) being the main known drawback of these technologies (Vassena et al. 2016).

### 3.2 The Case for Genome Editing

Those who argue in favour of the use of genome editing in the context of assisted reproduction agree that safety concerns must be thoroughly assessed before proceeding. Indeed, even the most vocal proponents of genome editing, and new reproductive technologies more generally, defend their clinical uses via the important caveat of assessing the risks that these technologies may pose to future children<sup>8</sup> (and the children of these children) (Chan et al. 2015; Harris 2016; Savulescu et al. 2015). For instance, Savulescu and colleagues (2015) argue that there is a moral imperative to continue gene editing research on human embryos in order to reduce off-target mutations and other safety issues, since “[a]dvanced gene editing techniques could reduce the global burden of genetic disease and potentially benefit millions worldwide” (Savulescu et al. 2015). Gyngell and colleagues (2016)

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7 It also encompasses the objection to so-called enhancing uses of technologies, i.e., uses that are not aimed at treating genetic conditions, but at changing non-diseased traits (such as height, eye-colour or intelligence).

8 A position that represents a *de facto* argument in favour of gene editing research (Savulescu et al. 2015).

focus on the clinical application of genome editing (especially in the context of assisted reproduction) and state that there is a “significant medical case to pursue germline modifications” to prevent the occurrence of genetic diseases in future generations (Gyngell et al. 2016). Two sets of arguments have been advanced in favour of using genome editing technologies on embryos to correct genetic abnormalities, provided that safety concerns are properly addressed (Gyngell et al. 2016; Reyes and Lanner 2017). The first argument is grounded on the importance of procreation for individuals’ well-being and for their flourishing. The argument of reproductive freedom thus states that people should be free to decide in matters of procreation and that no third-party should interfere with such freedom (if no harm is foreseen) (Harris 1992; Robertson 1996). Genome editing would enhance prospective parents’ reproductive freedom as it would allow them to pursue their preferred life plan (i. e., having children) in the way that most resonates with their wishes and desires (i. e., having genetically related children who are free from the genetic mutation they themselves carry). Another argument in favour of genome editing focuses on the benefits of using this technology in the context of assisted reproduction for the offspring and for future generations in general. For instance, Harris (2015) argues that:

“All of us need gene editing to be pursued, and if possible, made safe enough to use in humans. Not only to pave the way for procedures on adult tissues, but to keep open the possibility of using gene editing to protect embryos from susceptibility to major diseases and prevent other debilitating genetic conditions from being passed on through them to future generations.” (Harris 2015)

Genome editing would allow for the editing of the genetic makeup of IVF embryos in vitro, who would consequently develop into mutation-free offspring. Genome editing would prevent the occurrence of genetic diseases both in the first generation offspring as well as in future generations, while PGD can sometimes only prevent the occurrence of genetic diseases in the child that develops from the implanted embryo (Gyngell et al. 2016).

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## **4 How Do We Argue About New Technologies?**

Let me take stock of what I have said so far. There are certain arguments against the use of genome editing (where germline modification and concerns with the safety of this technique are concerned) as there are arguments in favour of its use (where prospective parents’ reproductive freedom and children’s welfare are concerned).

What then? How are we going to find a path through what Greene (2014) describes as the “morass of competing moral values” (henceforth simply “the morass” or the “moral morass”) and move towards a debate on new technologies that can constructively foster institutional design?

In this section, I focus on what I see as deep disagreement regarding both the moral standing of genome editing and the regulatory approaches that can be put in place. I explore different strategies that could be employed to overcome this deep disagreement, while indicating the foreseeable obstacles to the completion of this task. The first two options (and the related strategies) are what I see as the business of bioethics, or at least the business of many scholars working in bioethics. One option is to focus squarely on the disagreement by (in the best cases) politely pointing out to those who hold a different moral view, or (in the worst cases) leveling the accusation at them, that they are committing factual mistakes: they have failed to grasp how science and technology really work. The second option for dealing with existing disagreement is (again, at best) to try to persuade them of, or (at worst) to force onto them, certain moral views by using sound philosophical arguments.

In my view, both options and the related strategies to overcome the deep disagreement are theoretically flawed and may result in states of affairs that do not promote our well-being. In the first two sections I explain why I believe these two strategies will not bring us through the morass. Then, in the last section, I provide some insights from moral psychology and argue that that literature can help us going forward to build a debate that can constructively aid the development of policies for the regulation of new technologies.

#### **4.1 Option 1: It’s All a Matter of Facts**

One possible interpretation of the disagreement is to think about it in terms of a *misunderstanding of the relevant facts* of genome editing. This is an appealing interpretation as it could offer a potential strategy (the path through the morass that we are seeking) for overcoming the disagreement: getting the facts straight.

This interpretation is implicitly and, in certain instances, explicitly endorsed by those who criticise the arguments of other scholars for holding a different moral view concerning a new technology. Both groups often hint at the incapacity of “opponents” to understand how policy-making, scientific research, or the respective technology work. Consider the questions of uncertainty and safety. Both sides (those in favour of continuing genome editing research and those who oppose it) agree that, at present, it would be premature to use genome editing in the context of assisted reproduction and that the primary application of genome

editing should be research-oriented. The problems (and the disagreements) arise when future applications are speculatively considered, and when the question is posed concerning when, if ever, genome editing applications on human embryos will become more successful (e.g., when they might have fewer off-target effects, or cease to give rise to mosaic embryos). For proponents of human genome editing the questions of uncertainty and safety are seen as contingent, rather than fundamental, impediments. For them, conducting experiments genome editing will lead to overcoming impediments such as mosaicism, to decrease the off-target effects and to increase the reliability of the technology. They focus on *when* (rather than *if ever*) genome editing will be safe enough to proceed. On the contrary, those who are sceptical about the benefits of the technology, or who oppose it in principle, consider questions of safety to be the end of the debate rather than the beginning, a reason not to carry out potentially dangerous research rather than a reason to further pursue technical knowledge. They see the impediments described above as evidence for current (and often future) unsafety of the technology.

So, what are the relevant, the right facts? And, especially, can scientists, policy-makers and ethicists settle once and for all the questions of uncertainty and safety? Spoiler alert: I argue that it is highly unlikely that they are able to do so. Other debates about whether new assisted reproductive technologies should be allowed can help to illustrate how safety-questions are rarely a matter of factual disagreement alone.

Two techniques for the replacement of maternal mitochondrial DNA in embryos created with IVF, using the genetic material of the prospective parents and the mitochondrial DNA of a donor, have been recently approved (2015) in the United Kingdom. The decision of the Parliament to approve these techniques was surrounded by a heated debate both within the United Kingdom and abroad. In a lively exchange between John Harris and Inmaculada de Melo-Martín, two philosophers who work in the field of bioethics, the question of safety was extensively discussed (Harris 2016; de Melo-Martín 2017b). Harris, a known proponent of MRTs and other assisted reproductive technologies, argued that the right question to ask was not whether MRTs were “safe”, but whether they were “safe enough, given the balance of risks and benefits”, adding that MRT “from a safety perspective was regarded as good to go” (Harris 2016, 10–11).<sup>9</sup> On this very same point (uncertainty and safety) de Melo-Martín responded: “Contrary to Harris, I believe that the evidence

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9 Harris here refers to the multiple reviews of the “scientific methods to avoid mitochondrial diseases”, carried out in the United Kingdom by the Human Fertilisation and the Embryology Authority (HFEA) in 2011, 2013, 2014, and 2016, prior to the approval of MRTs in the United Kingdom.

about the safety of these technologies is at this point completely inadequate.” (de Melo-Martín 2017b, 161)

So, are MRTs safe or not? What are the facts of the matter? What does the evidence tell us? One possible answer is that either Harris or de Melo-Martín is simply wrong, has failed to understand correctly the scientific evidence regarding the safety of these techniques. Certainly, Harris thinks so about de Melo-Martín (and possibly vice versa), but this is precisely the point. Either one of them is right and the other is wrong (factually, that is), or there must be an alternative explanation for the disagreement.<sup>10</sup> And the very existence of such disagreements between two respectable scholars,<sup>11</sup> and especially within scientific, bioethical, and political communities, should set alarm bells ringing.

Safety is largely a contextual matter.<sup>12</sup> As Harris rightly points out, to say that a certain technology is “safe” hinges on how its risks and especially its benefits are evaluated – and how costs and benefits would be distributed. In other words, risks and benefits are contingent on the position of individuals in socio-economic, geopolitical, gender related and other aspects, and are very often unevenly distributed across the population (Prainsack et al. 2011).<sup>13</sup> Whether a technology is considered safe also depends, crucially, on whether approving the technology in question would violate principled positions in favour and against technological developments more generally (or principled positions regarding that specific technology). Yes, you

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10 It is important to note that I believe that Harris is right in considering safety-questions in terms of “safe-enough” questions. When I say that one of them is right and the other is wrong I do not refer to their assessments of what safety means, but rather to questions regarding the benefits of MRTs. These questions, as I explain below, are in my view not entirely matters of fact.

11 I am not saying that respectable scholars are never factually wrong, but I am favouring an alternative interpretation to explain this specific disagreement.

12 Importantly, considering safety a contextual matter does not mean either that it is impossible to hold a realist position regarding science and technology, or that we should give up trying to assess the safety of new techniques. For a discussion (and defence) of objectivity and realism in scientific research see for instance Kitcher 2001.

13 Additionally, as I argue elsewhere, the ethical assessment of new techniques ought not only to rest on a cost/benefit analysis, but also on an evaluation of existing alternatives, including those that do not rely on biomedical means. In other words, whether genome editing really represents a worthy alternative to existing options (such as PGD) depends on the extent to which the welfare of the future child can be put at risk in order to allow couples to have a genetically related child. Regulators and ethicists that argue in favour of eventually replacing PGD with genome editing, and couples for whom PGD does not represent an option, will have to consider whether reproductive autonomy should trump questions about the welfare of the child, in light of uncertainty (Cavaliere 2017a).



read that right: principled positions, positions regarding what is morally right and wrong, being derived from higher moral principles,<sup>14</sup> influence our understanding of the science of genome editing and our assessment of the risks that the technology may pose to future generations. This does not mean that it is impossible to assess the safety, the risks or, more generally, the facts of scientific breakthroughs, nor that we should give up trying to do so. It also does not mean that we blindly follow high moral principles to the point of drawing conclusions that are independent of previous reflections, conversations, and our own intellectual work in general. It simply means that principled positions play a role in these assessments. While not denying that some empirical questions will be eventually put to rest, it is nevertheless important to note that a consensus on the question of safety will be hard to reach, due to the competing values at stake in stakeholders' assessments. Those who take a precautionary stance concerning technological development will favour existing technologies over newly discovered ones, while those generally in favour of technological development will be ready to accept a higher degree of risk in the name of such development and of the potential benefits it may yield for those in a position to enjoy such benefits (Prainsack et al. 2011).

In the past two decades, moral psychologists have shown how moral intuitions (i.e., intuitions regarding the rightness and the wrongness of a certain practice) play a role in the formation of moral judgments, and how the rational argument that follows is a *post hoc* rationalisation of the initial, intuitively formed, judgment (Greene et al. 2001; Haidt 2001; 2012). These principled positions against or in favour of a certain practice (or technology) are not derived after a thorough assessment of the risks, the benefits, the safety etc. of the practice, but intuitively and automatically, prior to the thorough assessment of the available evidence (Haidt 2012; Greene 2014). According Haidt (2001, 2012) and other moral psychologists (Greene et al. 2001), moral judgment is not the end point of a rational process in which, like zealous judges, people collect the available evidence (for example, regarding the safety of genome editing), thoroughly assess it, and only then come to a certain moral conclusion (say, a green or a red light for genome editing in the areas of basic research or assisted reproduction). When we argue about moral questions and moral beliefs people are more akin to lawyers who try to defend their original thesis (i.e. genome editing is safe enough or is not safe enough) by constructing a *post hoc* rational justification for it (Baumster et al. 1994; Ditto et al. 2009; Haidt 2001, 2012). As Wright puts it:

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14 When I say that these positions are derived from higher moral principles I do not mean that they are consciously derived from these principles, but that peoples' moral judgments are informed and derived by more general principles about right and wrong.

“The brain is like a good lawyer: given any set of interests to defend, it sets about convincing the world of their moral and logical worth, regardless of whether they in fact have any of either. Like a lawyer, the human brain wants victory, not truth.” (Wright 1994, 280)

The principled positions that we hold inform our assessment of safety, risks and benefits. They inform, in other words, the facts of the matter regarding a certain practice. It is not only that evidence in psychology shows that we are all very good in finding evidence that resonates with our principled moral position and with our beliefs in general. Studies focusing on the so-called “confirmation bias” (Shaw 1996), on “motivated reasoning”, and especially on “motivated moral reasoning”, show that we are much more likely to be sceptical and to question evidence that contradicts our principled position than evidence that supports it (for a review of the relevant social psychology literature, and a discussion of “motivated moral reasoning”, see: Ditto et al. 2009). Motivated moral reasoning describes situations in which:

“Judgment is motivated by a desire to reach a particular moral conclusion.” Thus, these are “situations in which an individual has an affective stake in perceiving a given act or person as either moral or immoral, and this preference alters reasoning processes in a way that adjusts moral assessments in line with the desired conclusion.” (Ditto et al. 2009, 312)

Even if we have a conscious preference for objectivity in judgment, we often have unconscious directional motivations to reach certain conclusions that are preferred over others. This, again, does not mean that we are unable to reason ourselves away from such conclusions, nor that motivated moral reasoning is a robust and unmodifiable characteristic of the moral mind. It just means that we need to be aware of our own biases, preferences and moral views when we assess the evidence regarding, for instance, the safety of a new technology.

Harris, Savulescu, and others are known proponents of new technologies. De Melo-Martín, Baylis, and others who have argued against genome editing and MRTs, have held similar position with respect to other new technologies. Moreover, all of them are seasoned bioethicists capable of reading scientific papers correctly. Yet, for all of them, safety questions are either insurmountable or merely a contingent matter. So, who holds the truth of the matter concerning the safety of genome editing? The psychological literature on the role of moral intuitions in assessing the evidence, as well as the deep disagreement among bioethicists, scientists and policy-makers concerning safety questions, seem to provide at least a *prima facie* reason to be sceptical that to overcome the disagreement it would be sufficient to

merely getting the facts straight. This makes the idea of grounding a broad consensus on facts alone a very risky project.

## 4.2 Option 2: May the Best (Argument) Win

Another strategy for overcoming the disagreement (which, I hope we have established, is at least also a moral disagreement) is to play the philosophers' beloved game and stage a good old rhetorical battle in which the best argument wins. Applied to the context of genome editing and assisted reproduction, with the (regrettable) impossibility of organising a global debate competition, the strategy would be to assess the arguments in favour of and against genome editing. This appears to be a good idea, and indeed almost the entire business of certain philosophical and bioethical traditions has been about doing exactly this. To assess the arguments in favour of and against the use of genome editing in assisted reproduction we could check for logical mistakes, for inconsistencies, for the correctness of the premises, and for the soundness of the conclusions. Yet, should we then also attempt to evaluate moral arguments on the basis of the state of affairs that the normative positions will bring about? Or should we focus on the arguments' resonance with a universal moral law? Or on what the arguments say about the moral character of the speaker? The appraisal of philosophical arguments, the different methods for conducting such an appraisal, and the conditions for an argument to be valid are disputed. What matters for the present discussion is that we be able to agree on certain minimal standards an argument should meet in order to be considered in the debate on genome editing. Nevertheless, I fear we would be left again with sound, logically valid, but still contradictory arguments.

Häyry (2010), for instance, talks about the different moral arguments, in favour of and against new genetic technologies, in terms of "competing rationalities".<sup>15</sup> These are divergent rational moralities that can be simultaneously held. According to Häyry, then, we should resist the temptation to compare such rationalities and elevate one of them above the others. Instead we should limit ourselves to checking for internal the consistency of the argument and their external consistency with how things are in the world (Häyry 2011). So, for instance, while it is uncontroversial to reject as a fallacy the argument, "germline modifications are morally wrong because

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15 Häyry (2011), defines rationality in "nonconfrontational" terms: "A decision is rational insofar as it is based on beliefs that form a coherent whole and are consistent with how things are in the world; and it is aimed at optimising the immediate or long-term impacts on entities that matter" (Häyry 2011, 43)



yesterday my grandma told me so” (arguments from authority should set off the alarm bells), or equally, arguments that are incoherent and inconsistent. However, it may be much harder to likewise reject arguments that defend positions like the following ones: “germline modifications are morally wrong because they could be harmful to the children born as a result of the application of CRISPR”; or “germline modifications are morally obligatory because they enhance parents’ reproductive freedom, which is a fundamental moral right”<sup>16</sup>.

Fallacious, illogical arguments can and should be criticised, especially in matters of science and ethics (Harris 2011). This is what participants in the debate on the ethics of genome editing (and other assisted reproductive technologies) do on an almost daily basis. There are two problems with this strategy, if our goal is not to find the best philosophical argument (i. e., “do moral philosophy”), but to build a space where coexisting moral positions are discussed and some degree of common ground is found (i. e., to “do public policies with insights from moral philosophy”, and, I contend, moral psychology).<sup>17</sup> In these debates, the best argument – one that shows no logical mistakes, while exhibiting internal consistency, relying on valid premises and inferring valid conclusions – rarely *wins*. In other words, even if we agree on an independent strategy to establish who should win the prize,<sup>18</sup> and even if we pursue this strategy, we are left with a very good argument that may still fail to convince people who hold a different moral view (Camporesi et al. 2011). We are left with, as Camporesi et al. (2011) put it: “[A] cornucopia of ethical perspectives, each internally consistent but providing mere philosophical amusement.” (Camporesi et al. 2011, 255) This is a common problem in bioethics and in moral philosophy in general. An example: the argument that genome editing should be allowed, since it is in the interests of prospective parents to choose their preferred

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16 Personally, I am very sceptical of deontological arguments appealing to nature, sanctity, or rights. What I want to highlight here is that it is a very complex and perhaps unfeasible task to a) find an independent way to evaluate these arguments (i. e., an evaluative strategy that is not dependent on one’s own moral and meta-ethical convictions), and b) to agree on who should decide which strategy is the most appropriate. For a thorough case against appealing to rights, see Greene 2014 (Chapter 11, Part V).

17 One might say that the business of bioethics is not to build a space for a mutual exchange regarding differing moral positions, but to let the “best” moral argument win. Besides the procedural problems briefly described above, what we are trying to achieve here (i. e., what I am discussing in this chapter) is broad societal consensus as well as finding at least some common ground to move forward in the debate on genome editing, and building a regulatory framework that helps to alleviate “the burden of human existence” (Harris 2016), whilst still accommodating opposing views as much as possible.

18 See note 16 above for an explanation of “independent strategy” and of the procedural problems that we may encounter.

reproductive method, and to have their freedom in matters of procreation respected, is an argument that may be more intuitively appealing for someone who a) holds dear reproductive autonomy and freedom in general, and b) is sympathetic to the idea that reproductive freedom promotes well-being is an important value that should be respected. What I mean is that the pull of this argument may work on people who believe that freedom in matters of reproduction should trump other considerations, but not on those who, for instance, hold that assisted reproductive technologies are a mere commodity, and that research agendas should prioritise other, more pressing issues.

Besides these problems (of persisting moral disagreements and competing values), the problem with the “best argument” approach to the ethics of genome editing is that, even if it was possible to overcome the procedural challenges in selecting it, we may still not win as a community and as individuals. In other words, what we are faced with is not a philosophical problem, but a political problem. We may have very good arguments, sound and valid philosophical arguments, which still fail to promote our well-being and our happiness (broadly conceived, that is: independently from one’s own conception of well-being), which is arguably what these technologies, and perhaps medicine in general, should promote.

### **4.3 Perhaps not Everything is Lost. The “Listening Mode” and the “Meta-Morality”**

If my arguments (and some of the evidence from moral psychology) have managed to convince you, then at this point you should be at least a little sceptical of two options for overcoming the disagreement concerning the use of genome editing in assisted reproduction: explaining the facts of the matter to those who still fail to understand them, and letting the best argument win. Both strategies are, in my view, theoretically flawed and may end up bringing about state of affairs that do not promote our well-being. The deep moral disagreement surrounding genome editing technologies and their applications seems to be an obstacle we cannot ignore, if we want to move forward (by either banning or regulating applications of these technologies). What then should we do?

A possible diagnosis of the deep moral disagreement we experience in our everyday lives is that we have different moral intuitions and we hold different moral beliefs (Greene 2014; Haidt 2012). Religious scholars, feminist scholars, liberal philosophers, critical theorists, and lay people who find themselves embedded in differing political, socio-economic and cultural context, react in differing ways to contemporary (moral) controversies. Gay marriage, redistribution of income

and wealth, but also debates about abortion and genome editing, stir controversy because we hold different moral views, some of which are *post hoc* rationalisation of differing moral intuitions. Moral psychologists Jonathan Haidt and Joshua Greene offer different normative prescriptions for overcoming the disagreements and learning to cooperate between different moral tribes. In this final section of my paper I briefly outline their normative prescriptions. My conclusion is that they are both illuminating for the way we reflect on genome editing and the way we develop strategies to regulate new technologies beyond national borders.

Haidt's social intuitionist model (Haidt 2001, 2012) shows that people are good at finding evidence that confirms their initial moral judgment (remember the lawyer analogy!). What can make us change our minds about our moral beliefs is the multiplicity of occasions where we find ourselves challenged by others (what Haidt calls "reasoned persuasion", Haidt et al. 2008), and by the social environment in which we are embedded (what Haidt refers to as "social persuasion",<sup>19</sup> Haidt et al. 2008). Moral reasoning needs to be understood in terms of a social process, in which people embark alone on the search for evidence and come(?) together for the appraisal of such evidence. We need to be aware that we are self-righteous creatures, with a tendency to form moral beliefs from our intuitions and to rationalise them afterwards in our exchanges with others. To better get along with each other, and to find a path through the moral morass of genome editing, we need to acknowledge that our disagreements do not necessarily and solely stem from factual mistakes, wrong arguments, and wrong moral beliefs,<sup>20</sup> but from our competing rationalities and differing intuitions. Haidt's central normative prescription is to be more open towards those who hold views different from ours, to be aware that we are all biased by our moral intuitions (all of us, not only those who disagree with us), and to be aware that some of our grand arguments may simply be *post hoc* rationalisations of gut feelings. Thus, the Haidtian path through the moral morass of genome editing encourages us to abandon the mode of combat, and put ourselves in the listening mode, when we discuss the ethics of genome editing, its applications, and the regulatory frameworks which should be adopted.

Greene (2014) accepts Haidt's premises, shares his evolutionary understanding of morality, his view on the role of intuitions in the formation of (only some types of) moral judgments, and importantly, his (above outlined) normative prescription.

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19 Social persuasion refers to the fact that persuasion does not only happen when others give us reasons, arguments or new evidence, but also simply by virtue of our being "sensitive to and influenced by what other people think and feel" (Haidt et al. 2008, 192).

20 By wrong moral beliefs, I mean the moral beliefs that we do not share and that we may have failed to understand.

However, despite this broad agreement, he argues that Haidt's normative prescription alone will not bring us much further in our moral disagreements. In other words, listening and being open to opposing views are all good strategies as far as they go, but they are unlikely to bring us forward, if broad societal consensus<sup>21</sup> is what we aim for.

Over the last 20 years, Greene has examined the brain scans of people while they were reflecting on moral dilemmas such, as the trolley problem.<sup>22</sup> Greene observed that different areas of the brain (the ventromedial prefrontal cortex, VMPFC, and the dorsolateral prefrontal cortex DLPFC) showed more activity depending on which variation of the trolley problem was proposed. The footbridge case elicited more brain activity in people's DLPFC, the brain area associated with more logical, calculating cognitive capacities. On the contrary, more impersonal dilemmas such as the switch case elicited more brain activity in the VMPFC and in the amygdala, the brain regions associated with emotions. The only difference between the footbridge case and the switch case is whether the man scarified to save five is directly pushed down from the bridge to the track (and hence killed to prevent the trolley to kill the other five people) or he is killed by hitting a switch that diverts the trolley from a track where five people are standing to the track where he is standing. In a series of experiments conducted by Greene and others they verified over and over how brain activity in the DLPFC was linked to choosing utilitarian solutions (i. e. killing one to save five), whilst activity in the VMPFC was linked to dilemmas that involved directly pushing and hence killing a person to save the other five. This

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21 Greene does not aim at broad societal consensus alone. He has a normative theory in mind for how that broad consensus ought to look. However, a discussion of his proposal is beyond the scope of this paper.

22 The trolley problem describes a cluster of moral dilemmas that are all characterised by the choice of sacrificing one person in order to save five. The trolley problem was first discussed by Philippa Foot (1967) in an article discussing abortion and the doctrine of double effect. Different version of the problem and an analysis of the moral views that underpin them were later discussed by Judith Jarvis Thompson (1976). The two variations I am referring to here are the "switch case" and the "footbridge case". The trolley problem describes a situation in which a runaway trolley is barrelling down one track where there are five people tied up and unable to move. On another track there is one person, also tied up to the track and unable to move. In the switch case, a bystander could pull a lever and divert the trolley onto the track where only one person is tied up. In the footbridge case, the trolley is still barrelling down a track where five people are tied up and unable to move, but the only way the bystander can stop the trolley and prevent their death is by pushing a fat man (or a man with a large backpack) off a bridge. In both cases, the choice is between killing one person to save five or do nothing and let these five people die.

led Greene to formulate the theory of the dual-process brain (or of the two moral minds), delineating the process that works in automatic-mode and it is guided by our unconscious, automatic, emotional responses, and the process that works in manual-mode and has “conscious access to the operative decision rule. The rule that maps the relevant features of the situations onto a suitable behaviour” (Greene 2014, 136). According to Greene’s dual-process theory: “Reasoning frees us from the tyranny of our immediate impulses by allowing us to serve values that are not automatically activated by what’s in front of us” (Greene 2014, 137). We still need the input of emotions for decision-making, for evaluating risk (Damasio 1994), and for avoiding the conflicts that hinder cooperation among members of the same moral tribe, but we also need more than this (Greene 2014).

Greene’s normative prescription is that we need something more than emotions, than the automatic mode, to avoid conflicts between tribes that are moral in differing ways. Listening, avoiding self-righteousness and being more open for compromise are good steps. However, they are only first steps. We need all this and more to find a path through the moral morass. We need to work in manual mode to develop what Greene calls a “meta-morality”:

“A global moral philosophy that can adjudicate among competing interests of its members. A meta-morality job is to make trade-offs among competing tribal values, and making trade-offs requires a common currency, a unified system for weighing values.” (Greene 2014, 15)

The manual mode, the one that makes us choose to kill one person to save five in both the variations of the trolley problem, is the mode that causes us to reflectively endorse the greater good. The mode that overrides the emotional rejection of killing an innocent person in the name of the greater good (saving five people) is utilitarian morality (which Greene calls “deep-pragmatism”). Greene’s view that utilitarianism is a ‘splendid idea’, one we should all endorse, or at least strive to endorse in order to overcome our tribal conflicts, is an interesting view. It is also very controversial and has been criticised for a number of reasons, including the fallacy of deriving normative conclusions from factual claims (from the brain scans to deep-pragmatism as the morality that we ought to embrace), and critiques that are normally put forward against utilitarianism in general.

Despite the criticisms and despite detractors of utilitarianism, I think there is a lesson to be learned from Greene’s proposal. What we need is to develop a meta-morality that causes us to transcend our tribal disagreements and that allows us to discuss together “what matters” (Parfit 2011). The Greenian path through the moral morass of genome editing encourages us to find a common moral language,



shared values and shared moral beliefs as a starting point for discussing the ethics and policy questions of genome editing.

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## 5 Conclusion

A decision about allowing genome editing in the context of assisted reproduction has to rest not only on a thorough assessment of the safety of the techniques, and their possible or likely benefits, but also on a democratic process that takes into account differing views and values (Cavaliere 2017b; Jasanoff et al. 2015; Kitcher 2001). In this chapter, I have focused on genome editing in the context of assisted reproduction, and on the calls for broad societal consensus in tackling this question. I presented two main arguments against this possibility: namely, safety and that these applications would lead to germline modifications. I then turned to arguments in favour of genome editing, such as the welfare of future children and peoples' reproductive autonomy. As many have argued, it may be too soon for a conclusive assessment of this possibility, if only for the dearth of empirical data regarding its safety and feasibility. Thus, what this chapter offers a basis to begin a discussion on the ethics of genome editing that is informed by the literature in moral psychology. I argued that we should focus on finding a common currency and shared moral values, a meta-morality that goes beyond the deep moral disagreements among us, and that allows us to speak a common language that enables a minimum of agreement among us.

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### 3 Appendix 3

Cavaliere, G. (2018a). Genome editing and assisted reproduction: curing embryos, society or prospective parents?. *Medicine, Health Care and Philosophy*, 21(2), 215-225.

# Genome editing and assisted reproduction: curing embryos, society or prospective parents?

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**Abstract** This paper explores the ethics of introducing genome-editing technologies as a new reproductive option. In particular, it focuses on whether genome editing can be considered a morally valuable alternative to preimplantation genetic diagnosis (PGD). Two arguments against the use of genome editing in reproduction are analysed, namely safety concerns and germline modification. These arguments are then contrasted with arguments in favour of genome editing, in particular with the argument of the child's welfare and the argument of parental reproductive autonomy. In addition to these two arguments, genome editing could be considered as a worthy alternative to PGD as it may not be subjected to some of the moral critiques moved against this technology. Even if these arguments offer sound reasons in favour of introducing genome editing as a new reproductive option, I conclude that these benefits should be balanced against other considerations. More specifically, I maintain that concerns regarding the equality of access to assisted reproduction and the allocation of scarce resources should be addressed prior to the adoption of genome editing as a new reproductive option.

**Keywords** Genome editing · Assisted reproduction · Genetic kinship · PGD · Therapy · Selection

## Introduction: genetic diseases, genome editing and existing alternatives

Different reproductive options are available for couples or individuals at risk of transmitting genetic diseases to their offspring who wish to have children. In this paper, I explore ethical and social questions raised by the use of genome editing into the context of assisted reproduction and, in particular, as a potential alternative to preimplantation genetic diagnosis (PGD).

Some of the reproductive options available to this group of individuals include refraining from having genetically related children and/or using technologies to reduce or avoid the risk of transmission. The first set of options includes adopting existing children or turning to third-party reproduction (i.e. relying on a gamete donor). Adoption is currently legal in many European countries, but eligibility criteria vary. For instance, in some countries, access to this practice is limited to married heterosexual couples (e.g. Italy), while other countries have wider access criteria and allow same-sex couples (e.g. the Netherlands and the United Kingdom) and single parents (e.g. France and the United Kingdom) to adopt. In addition, other criteria such as marital status and age play a role in the decision to grant adoption.

Another possibility to avoid transmission of genetic diseases is for individuals to have partly genetically-related children and to seek gamete donors. This is commonly referred to as third-party reproduction, which allows couples to have children who are genetically related to a donor and to the unaffected individual in the couple. Third-party reproduction is currently only legal in some countries (e.g. the United Kingdom, the Netherlands and Spain) and usually restricted to heterosexual couples. Moreover, the state

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only subsidises IVF with donor gametes in a few countries (Gianaroli et al. 2016).

Alternatively, prospective parents at risk of transmitting genetic conditions to their offspring can seek to procreate with the aid of assisted reproductive technologies (ARTs) and preimplantation screening technologies (such as PGD), which would allow them to have genetically related children free from the condition that affects them (or one of them). PGD allows the testing of embryos created with IVF for genetic abnormalities prior to their transfer in utero. This technology is currently legal in many European countries (Gianaroli et al. 2016), but in some countries it remains restricted to so-called ‘serious’ conditions (e.g. in Italy and Germany), and in others is completely banned (e.g. in Poland and Switzerland; Biondi 2013; Gianaroli et al. 2016). Across Europe, eligibility criteria vary. In the United Kingdom, for instance, the Human Fertilisation and Embryology Authority (HFEA) periodically revises and updates the lists of conditions that are eligible for screening with PGD. Other countries, such as Germany and Italy, recently approved the use of PGD, but access to this practice remains restricted to a very limited number of severe, early onset conditions (Biondi 2013; Gianaroli et al. 2016).

### PGD and assisted reproduction

Where PGD is legal, it is typically used in cases where both prospective parents are carriers of an autosomal recessive mutation. These mutations are responsible for the occurrence of autosomal recessive monogenic diseases (i.e. diseases caused by a mutation in a single gene) such as cystic fibrosis and sickle cells anaemia.<sup>1</sup> When both prospective parents are carriers of such mutations, future offspring have a 1 in 4 chance of inheriting the mutated gene and developing an autosomal recessive disease, while they have a 1 in 2 chance of inheriting one abnormal gene and thus becoming healthy carriers. PGD allows the testing and selection of embryos created through IVF to transfer in utero those that are either free from the abnormal gene related to the prospective parents’ condition (or that are carriers of such mutated gene when no mutation-free embryo is obtained). PGD is also effective in cases where one of the prospective parents is heterozygous for an autosomal dominant mutation, meaning that they carry two different variants of a gene. Autosomal dominant mutations are responsible for the occurrence of diseases such as Huntington’s and

neurofibromatosis type 1. Future offspring have a 1 in 2 chance of developing autosomal dominant diseases even if only one of the prospective parents is affected, because it is possible that the embryo would carry the ‘good’ genetic variant from both parents. If the embryo inherited the disease-causing variant from only one parent, however, the resulting child would be affected by the disease.

It could be the case that none of the embryos created through IVF is free from the undesirable genetic mutation. For instance, when one of the prospective parents is homozygous for a dominant genetic disorder, the risk of transmission to offspring is as high as 100%, and hence no mutation-free embryos can be obtained. In addition, when prospective parents are both heterozygous for a dominant genetic disorder, the risk of transmission is as high as 75%, hence the chances of finding mutation-free embryos significantly low. Another case where PGD is not effective is when both parents are homozygous for a recessive genetic disorder, meaning that they both carry two variants of the disease-causing gene (Nuffield Council on Bioethics 2016; Vassena et al. 2016). In such cases, genome editing could represent an alternative to PGD and a new reproductive option for some prospective parents: mutations potentially leading to monogenic diseases would be corrected in embryos created with IVF prior to the transfer in utero or directly onto prospective parents’ gametes prior to fertilisation. Lastly, gene editing could replace PGD for women at risk of transmitting mitochondrial diseases as mitochondrial DNA mutations present in oocytes<sup>2</sup> could be corrected in the embryo (Vassena et al. 2016).

In the following section, I briefly present the debate on genome editing technologies applied to human embryos and I show how these technologies could be used as an alternative to PGD for the aforementioned cases where PGD is not effective. In “Assisted reproduction and PGD, or assisted reproduction and CRISPR?” section, I present the moral reasons in favour of and against introducing genome editing as an alternative to PGD. In particular, I present arguments in favour of using genome editing instead of, or as an alternative to, PGD, and argue that some of the moral arguments against PGD would not be applicable to genome editing. I conclude, ad interim, that such arguments offer a *prima facie* case in favour of introducing genome editing as a new reproductive option, given that safety concerns are thoroughly assessed. In “Curing embryos, society or prospective parents?”

<sup>1</sup> Autosomal recessive diseases develop when an individual has two copies of an abnormal gene.

<sup>2</sup> Currently, the United Kingdom is the only country that has allowed mitochondrial DNA replacement techniques. Such techniques represent the only existing method for couples where one member is affected by a mitochondrial condition to have genetically related children.

section, I turn to other arguments on the ethics of introducing genome editing as a new reproductive option and argue that there are additional questions that need to be carefully addressed. I conclude that introducing genome editing in the context of assisted reproduction would have some benefits, but that concerns regarding the equality of access to assisted reproduction and the allocation of scarce resources should be addressed beforehand.

## CRISPR and assisted reproduction

Gene-editing technologies have been around for over a decade. Zinc finger nucleases (ZFNs) and transcription activator-like effector nucleases (TALENs), two gene-editing technologies, were discovered in 2005 and 2010 respectively (Nuffield Council on Bioethics 2016). ZFNs and TALENs are relatively precise techniques, but have the disadvantage that they need engineered proteins to target specific sequences of the DNA, a procedure that requires time and resources (Nuffield Council on Bioethics 2016).

A new gene editing technique sparked debate early in 2015 due to its application on non-viable human embryos by a group of Chinese scientists (Baltimore et al. 2015; Lanphier and Urnov 2015). The technique in question is CRISPR/Cas9, an RNA-guided tool composed of two parts: clustered regularly interspaced short palindromic repeat (CRISPR) and CRISPR-associated protein 9 (Cas9). CRISPR/Cas9 makes use of a naturally occurring defence mechanism that bacteria use to avoid harmful infections caused by pathogenic organisms (e.g. viruses). The RNA tool (CRISPR) functions as a guide for the Cas proteins to target specific parts of the genome, which are subsequently cut by the Cas proteins. These cut strands can be exploited to modify the nucleotide sequence of DNA and to insert genes at the cut site. The application of this technique to human embryos and human gametes (i.e. oocytes and sperm cells) has been widely criticised for a number of issues, but chiefly for its potential to introduce *inheritable changes* in the human genome (germline modification). Indeed, the issue of germline modification has catalysed the attention of many scientists and ethicists (Brokowski et al. 2015; Lander 2015; Lanphier and Urnov 2015).

This paper focuses on PGD and CRISPR<sup>3</sup> applications to the field of assisted reproduction. In particular, it focuses on CRISPR as a potential alternative to PGD. CRISPR could represent a tool to avoid the occurrence of genetic

diseases in future children through the modification of the genetic makeup of embryos created with IVF from couples with a known risk of transmitting such genetic diseases. Since using CRISPR on early embryos could give to prospective parents who are either affected by monogenic diseases or who are carriers of them a chance to avoid the transmission of these diseases to their offspring, this particular application of CRISPR can be considered a new reproductive option for parents who want to have genetically related children.

## Assisted reproduction and PGD, or assisted reproduction and CRISPR?

Research on human embryos with CRISPR technology is still at an early stage and only few experiments have been carried out thus far (Vassena et al. 2016). Despite this, the issue of allowing clinical research has been discussed recently (Gyngell et al. 2016; Vassena et al. 2016; Reyes and Lanner 2017). The two main precautionary reasons that have been advanced against clinical applications of genome editing on human embryos or gamete cells are concerns regarding introducing changes in the human germline and safety questions. Many scholars and members of the public consider germline modifications unethical and a “line that should not be crossed” (Collins 2015; for a discussion of this claim, see: Camporesi and Cavaliere 2016). The worry is that edited embryos will pass their edited genome on to future generations, thus introducing changes in humanity’s gene pool. While it is of fundamental moral importance to consider the impact of present actions that could potentially have an impact on future generations, it seems reductive to limit these precautionary reflections to changes introduced with genome editing technologies on reproductive cells and embryos. In particular, those who worry about germline modifications via CRISPR and other genome editing technologies maintain that there is something exceptional in changes introduced *technologically* in our genomes via genome editing (and indirectly into the genomes of our offspring). The worry about germline modification encompasses a number of concerns, including the view that the human genome should be preserved intact as a “common heritage of our humanity” (cf. UNESCO statement against cloning, UNESCO 1997); the view that would be ethically problematic to change the germline of future generations “without their consent” (Collins 2015); and concerns regarding the safety of the technique not only for the child born thanks to its aid, but also for the child’s children (more about this below and in “Reproductive autonomy, child welfare and the interests of society” section). This first view misrepresents partially the natural history of humankind and how past and present humanly introduced innovations

<sup>3</sup> The arguments made for CRISPR can be extended also to other future genome editing technologies. Throughout the paper, I use CRISPR and genome editing or gene editing technologies interchangeably.

shape future generations (Buchanan 2011; Harris 1992). The introduction of agriculture, for instance, played a role not only in shaping our environment, but has fundamentally changed our genomes. The same could be said about technologies such as literacy and numeracy, which laid the foundations for technological innovations that have significantly changed us (Buchanan 2008, 2011). In other words, from a moral point of view, it seems irrelevant which *means* are used and whether inheritable changes are introduced with genome editing technologies or caused by other technological innovations, unless one is able to show the moral exceptionality of using genome editing technologies (Harris 2010). In addition to this, focusing solely on technical means to introduce changes the human gene pool overlooks how other policies (such as those dealing with greenhouse gas mitigation), innovations (such as those in the field of agriculture) and human habits could have similar effects (i.e. introduce changes in the gene pool) with potentially much more serious consequences (Dupras et al. 2014). The view that emphasises the need to ask the consent of future generations, as argued by Harris (2016), fails to state how such consent could be obtained. Most procreative decisions affect future generations, but it is unclear how and why the consent of future offspring should be obtained prior to act (Harris 2016).

The other argument against allowing genome editing for clinical uses is concern for the safety of future offspring (and of this offspring's offspring). At this stage, safety is indeed an issue and the efficiency of genome editing on embryos remains low, with mosaic embryos (i.e. embryos that have abnormal numbers of chromosomes in certain cells resulting in genetically different cells coexisting in the same organism) being the main known drawback of these technologies (Vassena et al. 2016). Despite this, some studies have proven the feasibility of gene editing in animals (Heo et al. 2014; Shao et al. 2014; Yoshimi et al. 2014; Zou et al. 2015), even though the efficiency of genetically modifying zygotes with Cas9 ranges between 0.5 and 40% (Araki and Ishii 2014). In addition, a recent study demonstrated the feasibility of preventing the onset of a genetic disorder such as cataract development (Wu et al. 2013) and the injection of Cas9 into primate zygotes led to the birth of genetically modified offspring (Liu et al. 2014; Niu et al. 2014).

### The case for genome editing: two sets of arguments

There are two sets of arguments for introducing CRISPR and other gene editing technologies into the clinic, provided that safety concerns are properly addressed. In this section I first outline the first group of arguments, which concerns the benefits of genome editing for future children (and their children too) and for prospective parents

(Gyngell et al. 2016; Reyes and Lanner 2017). In the following section, I present additional reasons why genome editing could be a morally preferable alternative to PGD: genome editing would not be subjected to some of the critiques moved against PGD.

The moral reasons that ground the case for PGD (the welfare of future children and the reproductive autonomy of prospective parents. Pennings et al. 2007; Buchanan et al. 2001; Harris 1992) can be extended to defend the clinical use of genome editing in reproduction. It is widely accepted that reproductive autonomy and respect for parental discretion in reproduction are values worth defending<sup>4</sup> (Buchanan et al. 2001; Harris 1992; Robertson 1996). With respect to reproductive autonomy, genome editing would be comparatively better than PGD: it would offer an alternative to this technology for those aforementioned cases where PGD is not effective or for prospective parents who wish to increase their chances of having mutation-free embryos. In this sense, genome editing could be said to enhance reproductive autonomy. With respect to the welfare of the child, the case in favour of genome editing seems *prima facie* stronger than the case in favour of PGD. Unlike the latter technology, whereby embryos implanted can be carriers of the parents' mutated gene, genome editing would allow modification of the genetic makeup of embryos who would consequently develop into mutation-free offspring. In other words, genome editing would prevent the occurrence of genetic diseases in future generations, while PGD can sometimes only prevent the occurrence of genetic diseases in the child that develops from the implanted embryo (Gyngell et al. 2016).

There are, however, other arguments in favour of preferring genome editing to PGD. PGD is a contested practice as its scopes are not therapeutic (i.e. PGD does not *treat* embryos) but rather selective (i.e. PGD selects the embryos that should be transferred in utero. Asch and Barlevy 2012; Parens and Asch 2003). PGD as a means to select embryos that have a decreased risk of developing into a child with a genetic condition is seen as ethically troubling for two reasons: firstly, because it goes against the traditional ends of medicine and 'selects out' rather than 'cures' persons affected by genetic conditions (MacKellar and Bechtel 2014), and secondly, because decisions on which embryos should be selected are said to embody value judgements regarding people living with certain disabilities (Knoppers et al. 2006; Parens and Ash 2003), a critique of screening technologies that became

<sup>4</sup> At least when it is about medical conditions, but this is the case in question, so I will not enter into a discussion on so-called cosmetic traits and enhancement.



known as the ‘expressivist argument’ or ‘expressivist objection’ (Buchanan 1996; Shakespeare 2006).

### Selection versus therapy

PGD (at the moment) and CRISPR (potentially in the future) are two technologies that enable similar ends: in both cases, these technologies increase the chances of giving parents genetically related offspring unaffected by specific genetic conditions. Despite the similarity of the outcomes (i.e. healthy child), the means used are rather different. PGD is a form of genetic testing that allows screening for abnormalities in early embryos and to subsequently implant only those with a decreased risk of developing a certain condition. Instead, CRISPR and other gene editing technologies are tools for gene therapy that allow the modification of embryos or of gamete cells in order to avoid the occurrence of certain conditions in the future child (and in future generations).

Following this distinction of means, there is a sense that while PGD entails the *selection* of embryos, CRISPR is more akin to *therapy*. At this point, however, it is important to note that CRISPR and other genome editing technologies can be considered both therapeutic and non-strictly-therapeutic (or, following Wrigley et al. “pre-emptively therapeutic”; Wrigley et al. 2015, p. 636). I am not trying to violate Aristotle’s principle of non-contradiction on the impossibility that contradictory assertions can be both true at the same time here. What I mean is rather that whether these technologies are therapeutic depends on what sort of factual and moral considerations are taken into account. If the focus is on the prospective parents, then CRISPR can be considered therapeutic in some instances because it could be a solution (or a treatment?) for those couples who would not otherwise be able to conceive children that are related to them and that are free from the risk of developing (or have a decreased risk to develop) the condition that affects them.

If the focus is on the future children, we have two possible interpretations: following the view that equates embryos with persons, CRISPR *is* therapeutic because it treats the embryos (i.e. it treats persons), whereas PGD is selective because it selects in/out the embryos (i.e. it selects out persons). If, however, we are more inclined to think of embryos as beings with the *potential* to develop into persons (i.e. potentiality view, arguably a more widely shared position), then CRISPR is not straightforwardly therapeutic, because there is no person to be treated at the moment that we use the technology.<sup>5</sup> Despite this remark, I argue that there is a sense whereby genome editing can still be

considered therapeutic, or, as mentioned above, pre-emptively therapeutic. In order to assess whether CRISPR can be considered pre-emptively therapeutic, it is necessary to determine whether embryo X (i.e. the embryo that exist prior to the application of CRISPR) is identical to new-born  $X^{+ \text{ about 9 months}}$  (i.e. the child that is born after the application of CRISPR on embryo X). This assessment matters for the ethical debate on PGD and genome editing because if these two entities (embryo X and new-born  $X^{+ \text{ about 9 months}}$ ) are identical, *then* PGD would be more problematic than CRISPR as the first would be a selective technology, whereas the second would be a therapeutic technology. A brief explanation of the question of identity is needed before proceeding with the discussion on PGD and CRISPR and the ethics thereof. Currently, ethicists and philosophers involved in the debate on reproductive genetic technologies seem to be divided on whether genome editing technologies applied to embryos are identity-affecting technologies or not, as this largely depends on the circumstances taken into account.<sup>6</sup> When I say “identity-affecting” I refer to the idea of numerical identity and to the metaphysical problem of determining how we can rightly refer to one and the same person in any different set of circumstances, despite the changes that the person undergoes over time. Thus, for instance, there is numerical identity between a person X and a person Y only if person X and Y are the same person. To put it simply, I am numerically identical to the person that is writing this paper at the moment. The challenge of any account of numerical identity is then to explain what determines the entity that we in fact are despite the changes that we undergo over time.

<sup>5</sup> This observation is conditional as it relies on the interpretation of therapy as a practice that can only be defined as such if there is a *person* to be treated (Rulli 2016a).

<sup>6</sup> I refer here to the debate on mitochondrial replacement techniques (MRTs) and not strictly on genome editing with CRISPR, as few commentators have dealt specifically with the question of whether genome editing is identity-affecting (for two examples, see: Gyngell et al. 2016; Liao 2017). One of the two techniques for the replacement of faulty mitochondrial DNA, pronuclear transfer (PNT), arguably represents the most similar case to genome editing as, unlike the other technique for the replacement of mitochondrial DNA (maternal spindle transfer—MST), it is applied after the oocytes has been fertilised. The contention, in the case of PNT, is whether this technique is identity-affecting or not, and commentators have presented differing views on this matter (Liao 2017; Palacio-González 2017; Rulli 2016a; Wrigley et al. 2015). While I am aware that PNT and CRISPR are two distinct technologies, PNT arguably represents the most similar case to genome editing as both CRISPR and PNT are applied *after* fertilisation. Hence, other things being equal, arguments concerning whether PNT is identity-affecting or not can also be considered valid in discussions on whether CRISPR is identity-affecting. It must be noted however, that those who explicitly referred to genome editing maintained that it is *not* identity-affecting (Gyngell et al. 2016; Liao 2017). Interestingly, authors who speculatively consider the possibility of using gene therapy on human embryos before the availability of CRISPR are also divided on this issue (Buchanan 1996; McMahan 2006; Sparrow 2008).

In this sense, if I grow taller or if I lose an eye due to an accident, I am still numerically identical to the entity I was before having that accident or when I was shorter. This is the case because changes such as losing an eye or growing taller are largely considered *contingent* to numerical identity, namely they do not change the entity that I am.

Returning to genome editing, those who do not subscribe to the embryos as persons view can view the technology in two different ways. The contentious matter is whether applying CRISPR on embryo X creates a numerically different entity (call it embryo Z, that will eventually develop into person Z) or it just leads to a numerically identical entity (call it embryo X\*, that will eventually develop into person X\*) in the same sense that applying gene therapy on adult X does not create a different adult Z, but only leads to a numerically identical adult X\*. While in the first case genome editing would be considered an identity-affecting technology (i.e. a technology that by virtue of its use creates an entirely new entity), in the second case it would amount to a non-identity-affecting technology.<sup>7</sup> Following the first interpretation, CRISPR cannot be considered a therapy as, by virtue of its use on an embryo, it determines the kind of person that is brought into being rather than pre-emptively curing the same pre-person. On the contrary, if we are inclined to follow the second interpretation, then CRISPR is therapeutic as it pre-emptively cures an embryo that will develop into a numerically identical child that does

not have the genetic condition that is consciously avoided.<sup>8</sup> It is only in this second sense that it is possible to say that if the genome of an embryo affected by a certain genetic condition is modified and this condition eradicated, then this embryo will develop into a numerically identical child who, had CRISPR not been used, would have been affected by a genetic disease. As a consequence, even if one does not subscribe to the embryo-as-persons view, *there is a sense* whereby genome editing can be considered at least *more similar* to therapy than to selection: genome editing would be a pre-emptive treatment for the genetic disease that is caused by the genetic mutation at the embryonic stage.

If the second interpretation about genome editing being non-identity-affecting is embraced, then both the teleological objection (i.e. PGD is morally problematic because it does not fall within the traditional ends of medicine) and the selective attitudes objection (i.e. PGD is morally problematic because it promotes selective and discriminatory attitudes) seem to be less applicable to the use of genome editing on embryos to prevent the occurrence of certain conditions in future children. As explained above, editing the genome of embryos can be considered pre-emptively therapeutic and thus falls within (or at least closer to) the traditional ends of medicine. From this, it also follows that it would be problematic to consider such practice as selective or discriminatory: disability scholars would have to condemn all the interventions aimed at treating genetic diseases (Barnes 2014).

These clarifications have normative implications, namely that, once the safety of editing the genome of human embryos is carefully assessed, the latter technology should be considered preferable to PGD. In the next section, I will outline some additional questions that need to be addressed and explain why preferring CRISPR over PGD is not completely cost-free.

## Curing embryos, society or prospective parents?

In the previous sections, two main questions have remained unaddressed. One question is on the value and meaning of genetic parenthood. Another, albeit related, question concerns the ethics of existing alternatives. I explore these two questions in this last section and conclude that they provide at least some *prima facie* moral reasons for carefully

<sup>7</sup> Despite some challenges, the biological origin (or gametic origin) that a person has is widely considered a necessary condition of what determines the human being that we are. This is well explained by philosopher Derek Parfit's 'Origin View' (or gametic essentialism): "each person has this necessary property: that of having grown from the particular pair of cells from which this person in fact grew" (Parfit 1984, p. 353). In other words, the fact that two gametes came together and generated me is, under this view, considered a necessary condition of my identity: I am the entity that I am by virtue of my gametic origin. Now, this is linked to the discussion of treatment and selection because a technology such as PGD is identity-affecting. In other words, using PGD causes a numerically different person to come into being, namely a different person than the person that would have come into being had PGD not been used. In the case of genome editing, since the intervention takes place *after* fertilisation, the gametic origin of the genetically modified embryo and the gametic origin of the non-genetically modified embryos are identical. In other words, these two embryos are numerically identical. The contention, however, is that gametic origin is only a necessary and not sufficient condition for having a specific identity. Thus, whether genome editing technologies applied to zygotes/embryos cause a different person to come into being or not remains an open question. If they do, then such technologies cannot be considered therapeutic because a different person comes into being due to the use of genome editing. If they do not, they can be considered therapeutic.

<sup>8</sup> If genome editing is employed before the 14th day after fertilisation (as it is required by embryos research regulations in the United Kingdom and in many other countries, Hyun et al. 2016), the embryo could still cleave into two (i.e. twinning). In this case, the children that could potentially develop from such embryo will be two. How-

Footnote 8 (continued)

ever, twinning occurs spontaneously and it is not influenced by the use of genome editing on the embryo. As a consequence, the use of the technique does not directly affect the numerical identity of the future child/children as it is not the direct causation of the embryo splitting.



considering the introduction of a new reproductive option when similar options are already available.

A peculiar feature of assisted reproductive technologies such as PGD, and possibly genome editing, is that they are often offered to prospective parents who are affected by a genetic condition in order to conceive (or increase their chances of conceiving) healthy offspring. It is in this sense that these technologies represent a *solution* for those prospective parents whose *problem* is the impossibility of having a *genetically related* and *healthy* child; or at least healthier than the child that would otherwise be brought into the world had these technologies not be employed. As explained in the first section of this paper, there are other options than PGD to increase the chances of having healthy children, but they entail refraining from having genetically related children (for one individual in the couple or, in the case of adoption, both parties). Reproductive technologies such as PGD and genome editing convey the interests of different groups: the prospective parents, the future offspring and the society where these offspring will grow and thrive. Despite the importance of all three stakeholders, their interests are not granted equal importance: the welfare of future children and the reproductive autonomy of the prospective parents are usually considered of greater moral importance than the aggregate interests of society in having healthy members, respecting competing values on assisted reproduction, and limiting the use of certain technologies against a backdrop of scarce resources. This is what I define as the received view on the ethics of assisted reproductive technologies. An ethical assessment of whether introducing new technologies in the context of reproduction should thus consider these three aspects (with the aforementioned prioritisation in mind) in turn.

### Reproductive autonomy, child welfare and the interests of society

Genome editing, at first sight, seems to score high on the reproductive autonomy and welfare of the child fronts: unlike PGD, it allows for more conditions to be corrected and the reduction of the occurrence of certain genetic conditions in future generations; it also increases the reproductive autonomy of the parents by offering not only one more possibility in the geneticists tool-box, but also by allowing those couples for whom PGD is not always successful to have biologically related, healthy offspring. So far so good. Or maybe not? The idea that more choice leads to greater freedom has been challenged (Dworkin 1982; Rose 1999; Rothman 1985). More options can also translate into more uncertainties, and greater perceived and actual responsibilities for the prospective parents (Dworkin 1982). In this sense, introducing genome editing into the clinic as an alternative to PGD may be detrimental for the very same

prospective parents that it is designed for. While genome editing may be more routinely employed in the future, some issues will likely remain. These issues include, for instance, reflections upon which conditions should be eligible for the use of genome editing and whether parents who fail to employ the most efficient technology available could be considered morally responsible (Rothman 1985).

What about the welfare of the future child? The empirical question of whether safety concerns will be put to rest and genome editing will ever be *safe enough* to represent a concrete alternative to PGD divides scholars (Harris 2016). The reasons for this are twofold: first, no one knows the answer to such questions *yet*. Secondly, this empirical question is strongly influenced by the value judgements of scientists, ethicists, policy-makers and the public on the degree of certainty required to move forward. Hence, even without denying that such empirical questions will be eventually be put to rest, it is still important to note that a consensus on the question of safety will be hard to reach due to the competing values at stake in stakeholders' assessments. Those taking a precautionary stance concerning technological development will favour existing technologies over the newly discovered, while those who are generally in favour of technological development will be ready to accept a higher degree of risk in the name of such progress and of the potential benefits that it may yield. With respect to the safety and the welfare of the future child, whether genome editing really represents a better option than PGD will thus divide scholars, scientists and the public (and, as exemplified by the debate on embryo-applications of CRISPR, already does). A decision on whether to allow genome editing will thus have to rest not only on a thorough assessment of the safety of the techniques, but also on a democratic process that takes into account such differing views and values (Cavaliere 2017; Jasanoff et al. 2015; Kitcher 2001). The ethical assessment of new techniques ought to not only rest on a cost/benefit analysis, but also on an evaluation of existing alternatives, including those that do not rely on biomedical means. In other words, whether genome editing really represents a worthy alternative to existing options (such as PGD) depends on the extent to which the welfare of the future child can be put at risk to allow couples to have a genetically related child. Regulators and ethicists that argue in favour of eventually replacing PGD with genome editing, and couples for whom PGD does not represent an option, will have to consider whether reproductive autonomy should trump questions on the welfare of the child in light of uncertainty.

Lastly, what role should societal interests and views play in the decision over whether genome editing should replace PGD? There are different ways in which assisted reproductive technologies and procreative decisions more generally impinge on society. Procreative decisions influence the *type*

and the *number* of people that will be created. They allow new consumers, producers, workers, mothers, fathers, etc. to come into existence. We live in an increasingly interlinked world and the aggregate effects of individual decisions affect a wider range of people than ever before (Singer 2004). There are historical reasons why third parties' interventions in procreation are looked at with suspicion, and the shadow of eugenics seems to extend over any discussion regarding reproductive technologies and their governance (Paul 1992). Despite these worries, the regulation of new reproductive technologies will be influenced by governments' policies, which in turn will reflect the interests of society and societal views on emerging reproductive technologies. Regarding the governance of genome editing technologies and their potential use in the context of assisted reproduction, the interests of society might play a role in two main ways: the first is whether genome editing is ethically acceptable for a large segment of society (Kitcher 2001), and second, related, is whether existing alternatives warrant the introduction of a new practice and the clinical research necessary to safely implement it. Almost every new technology introduced or discussed for potential introduction in reproduction seems to stir controversies. The recent debates on genome editing (Camporesi and Cavaliere 2016), mitochondrial replacement techniques (Appleby 2015) and 'older' debates on PGD (Scott 2006) are just a few instances of these controversies. However, once certain uses are constrained and lines drawn (for instance between therapeutic and enhancing uses), these technologies have been approved and, at least in certain countries, accepted by large swaths of the population. Thus, even if genome editing will be met with controversies and will encounter resistance, it does not *prima facie* translate into the need for banning any research involving it. On the contrary, this should translate into support for a democratic and deliberative approach to the governance of technological innovation (Jasanoff et al. 2015) and into the respecting of competing moral views on these issues (Cavaliere 2017).

#### **Societal interests and the costs of introducing genome editing in the context of assisted reproduction**

At this point, there is, however, there is one last thing to consider, which concerns the aforementioned interests of society and how they should and could play a role in the ethical assessment of introducing genome editing in the context of assisted reproduction. While it is true that genome editing could open up new reproductive possibilities for certain couples (i.e. enhance reproductive autonomy) and provide heritable benefits to their future offspring (i.e. considerations regarding the welfare of future child), these benefits ought to be balanced against the costs of introducing a new reproductive technology. These costs

include the investment of public resources, considering both the scarcity of such resources and the existence of available alternatives. Emanuel et al. (2000) argue that for clinical research to be ethical, among other requirements, it needs to have social value, namely it should be directed at "a diagnostic and therapeutic intervention that could lead to improvements in health and well-being" (Emanuel et al. 2000). Being of social value is an ethical requirement for clinical research to go forward precisely because it operates in a context of scarce resources. From this it follows that if the social value of a technology is limited, then the investment of public resources for the development and implementation of such technology may be unethical (Rulli 2016b). The proposed clinical research (in this case that needed in order to implement genome editing as an alternative to PGD) needs to be evaluated on two levels: absolute and relative. The absolute level is settled once the proposed research is expected to bring about improvements to health and well-being. The relative level, however, needs more: the proposed research (and the improvements to health and well-being thereof) needs to be compared both with other potential uses of those scarce resources and with existing alternatives to bring about similar improvements to health and well-being. Two of the criteria that are often employed to assess whether to invest resources in certain clinical research and whether it will bring about significant improvements to health and well-being are the severity of the condition and the number of individuals that it affects (Rulli 2016b). If we consider these two criteria, the benefits of the introduction of genome editing as a new reproductive option are arguably minor and thus may not warrant the investment of public resources. The number of cases for which PGD is not an option, as mentioned in the first section, is limited. In addition, considering the importance of taking into account future children's welfare, the unresolved questions concerning safety seem to indicate that health improvements may not be so significant. An obvious critique to this is the following: clinical research is aimed at improving techniques in order to achieve significant benefits for future children. This is certainly correct and we would not enjoy the benefits of many technologies and drugs if it was not for clinical research. But again: resources are limited and not all research can be publicly funded.

Returning to the relative level to evaluate clinical research, it is important to consider that improvements in the health and well-being of future children can also be achieved by looking at alternative solutions, for instance third party reproduction or adoption. For those limited number of parents for whom PGD is not an option, the choice is not between genome editing and a sick child. The choice is much wider than that. This does not mean that the choice of adopting or relying on third party reproduction comes without a cost, or that prospective parents' wishes

should be neglected. It only means that there are other interests at stake and that there are other strategies than developing new technologies to tackle health needs.

These considerations do not lead to the conclusion that public interest (in the form of a prudent use of resources) should be prioritised over prospective parents' reproductive autonomy and future offspring's welfare. On the contrary, the received view, namely the view that considers the interests of these two groups as more morally relevant than those of society, ought to be taken as the default position. But this position should not prevent us from seeking alternatives. Perfecting existing technologies such as PGD, and possibly widening the criteria of access to adoption or third party reproduction, would be a less costly and possibly quicker strategy to grant future children's welfare while at the same time respecting prospective parents' wishes. Making existing technologies and practices available via broader state funding schemes would allow their use by larger swaths of the population.

## Conclusions: context matters

In this article, I have analysed the moral case for introducing genome editing as an alternative to PGD. I have presented the reasons in favour and the two main arguments against this possibility, namely safety and germline modifications. After presenting some of the available data on the safety of CRISPR, I have argued that concerns with germline modifications do not represent a compelling argument against the introduction of genome editing into the clinic. I have then turned to arguments in favour of genome editing and concluded that there seems to be a *prima facie* case in favour of starting clinical research with CRISPR. In the last section, I have focused on the moral reasons that are normally taken into account in debates on reproductive technologies, namely the welfare of future children, the reproductive autonomy of the parents and the interests of society. I have showed that a closer look at genome editing in light of these moral reasons seems to generate some additional reasons for caution in accepting genome editing as a new reproductive option. These reasons may entail shifting from funding new resources, such as CRISPR, and advocating for its introduction in the name of values such as reproductive autonomy and the welfare of future children, to focusing on widening the criteria of access to existing options and possibly re-thinking resource allocation and state funding of assisted reproduction. This paper does not attempt to provide decisive arguments in favour of or against the introduction of CRISPR as a new reproductive option. As many have argued, it may be too soon to have a conclusive assessment of this possibility, if only for the dearth of empirical data regarding its safety and feasibility.

Rather, this paper offers a basis to begin a discussion on the ethics of introducing genome editing as an alternative to PGD and stresses the need to consider that scientific research does not happen in a vacuum where the soundest theoretical argument wins. Rather, it happens in a context where resources are limited, where genetic parenthood is an important value cherished by many, and where technical solutions are often given preference over other strategies.

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## Compliance with ethical standards

**Conflict of interests** The author declares that she has no competing interests.

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#### 4 Appendix 4

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# Lesbian motherhood and mitochondrial replacement techniques: reproductive freedom and genetic kinship

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## ABSTRACT

In this paper, we argue that lesbian couples who wish to have children who are genetically related to both of them should be allowed access to mitochondrial replacement techniques (MRTs). First, we provide a brief explanation of mitochondrial diseases and MRTs. We then present the reasons why MRTs are not, by nature, therapeutic. The upshot of the view that MRTs are non-therapeutic techniques is that their therapeutic potential cannot be invoked for restricting their use only to those cases where a mitochondrial DNA disease could be 'cured'. We then argue that a positive case for MRTs is justified by an appeal to reproductive freedom, and that the criteria to access these techniques should hence be extended to include lesbian couples who wish to share genetic parenthood. Finally, we consider a potential objection to our argument: that the desire to have genetically related kin is not a morally sufficient reason to allow lesbian couples to access MRTs.

## INTRODUCTION

One of the main purposes of bioethics is to demarcate morally acceptable applications of biomedical technologies. For example, in the past decade, there has been much debate in bioethics on whether there is a morally significant difference between therapeutic and enhancing genetic modifying interventions. 'Bioconservatives' such as Michael Sandel and Jürgen Habermas maintain that biotechnological practices aimed at curing disease are morally acceptable, whereas those aimed at increasing certain traits such as height and strength are morally suspicious.<sup>1,2</sup> Other moral boundaries investigated by bioethicists concern morally appropriate versus inappropriate uses of reproductive screening technologies—such as preimplantation genetic diagnosis (PGD)—and of reproductives technologies—of which mitochondrial replacement techniques (MRTs)<sup>3</sup> are an example. The latter techniques help women wishing to become mothers who carry mitochondrial DNA (mtDNA) abnormalities in their eggs to have genetically related offspring free from mtDNA diseases.<sup>3</sup>

MRTs have been at the forefront of bioethical debate since the UK began to discuss their legalisation in the 2000s. In February 2015, regulations were passed on two MRTs: maternal spindle transfer (MST) and pronuclear transfer (PNT).

<sup>1</sup>Even though the name 'mitochondrial replacement techniques' is contested, here we use it because it has secured a foothold within the academic debate; see Palacios-González's *Mitochondrial replacement techniques: egg donation, genealogy and eugenics*.<sup>62</sup> Ainsley Newson and Anthony Wrigley have recently proposed and defended the term 'mitochondrial targeting techniques'.<sup>63</sup>

These regulations came into force in October 2015, making the UK the first country in the world to explicitly legalise MRTs under a licensed scheme.<sup>4ii</sup>

Although these technologies are legal in the UK, at the present time, only people at risk of transmitting a severe mtDNA disease can access them. The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 state that the permitted circumstances for using these techniques are when:

1. There is a particular risk that any egg extracted from the ovaries of a woman named in the determination—or embryo which is created by the fertilisation of an egg extracted from the ovaries of a woman named in the determination—may have mitochondrial abnormalities caused by mtDNA.
2. There is a significant risk that a person with those abnormalities will have or develop serious mitochondrial disease.<sup>4</sup>

Part of the rationale for these regulations is to allow couples at risk of transmitting mtDNA diseases to have children who are free from them.<sup>5</sup> In addition, MRTs may aid lesbian couples, and couples where both members have functional ovaries (ie, couples or relationships where one member may be intersex or transgender) to have genetically related children.<sup>iii</sup> It has also been theorised that they can be used to increase the chances of avoiding embryonic arrest and thus allow couples whose infertility is not related to mtDNA mutations to have genetically related children too, but *this possibility awaits empirical demonstration*.<sup>iv</sup> These two potential applications of MRTs are not at present legal in UK. However, it must be said that it seems that the MRTs regulations were not written down with the explicit intention of singling out these possibilities as illegal but rather in the attempt to make MRTs legal in order to avoid mtDNA diseases.<sup>5</sup>

Legal scholars, bioethicists and stakeholders participating in the debate on MRTs have tried to establish a morally significant boundary between acceptable and unacceptable applications of these techniques.

<sup>ii</sup>Interestingly, the first couple of babies born because of MRTs were not born in UK, but in USA (by means of maternal spindle transfer) and Ukraine (by means of pronuclear transfer).<sup>64,65</sup>

<sup>iii</sup>Even when in this paper we mainly refer to lesbian couples our arguments equally apply to all couples where both members have functional ovaries or cryopreserved eggs.

<sup>iv</sup>Due to space constraints, we do not investigate, or focus on, the ethical aspects of offering MRTs to heterosexual couples with non-mtDNA-related infertility problems. We also do not discuss other ethical issues related to MRTs more generally, such as risks to egg providers.



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For example, the mitochondrial disease community (patients, researchers and clinicians) have strongly advocated for a therapeutic (ie, acceptable) and a non-therapeutic (ie, unacceptable) demarcation of MRTs. By doing so they aim, in part, to avoid challenges from slippery-slope type arguments that allowing MRTs would then lead to 'designer babies'.

In this paper, we argue that lesbian couples who want to have children who are genetically related to both of them should be allowed access to MRTs. The paper is structured as follows. First, we provide a brief explanation of mitochondrial diseases and MRTs. Second, we show that MRTs are not therapeutic in nature and thus this feature of the techniques cannot be invoked for restricting their use only to those cases where an mtDNA disease could be 'cured'. We then argue that a positive case for MRTs is justified by an appeal to reproductive freedom and that access to these techniques should hence be extended to lesbian couples. Finally, we consider a potential objection to our argument: namely that the desire to have genetically related kin is not a morally sufficient reason to allow lesbian couples to access MRTs.

### MITOCHONDRIAL DISEASES AND MRTS

Mitochondria have been described as the 'powerhouses' of our cells. They are small structures whose main known purpose is to produce the necessary energy for cellular, organ and bodily function.<sup>6</sup> They are inherited via the maternal line and have their own DNA (mtDNA), which resides outside the cell's nucleus. Mitochondrial diseases are a cluster of neuromuscular diseases in which symptoms vary in severity and expression and can develop immediately after birth or later in life.<sup>7,8</sup> Mutations both in the nuclear DNA and the mtDNA can cause mitochondrial diseases. Deleterious mutations in the mtDNA, in each cell, can happen across all mitochondria (this is known as homoplasmy) or they can occur only in certain mitochondria (known as heteroplasmy). In this paper, we will only discuss mitochondrial diseases produced by problems in the mtDNA, referred to as mtDNA diseases.

To avoid the transmission of an mtDNA disease, two MRTs have been developed: PNT and MST. PNT requires the creation of two zygotes, through assisted reproductive techniques (ARTs), one with the gametes of the intending parents (or intending mother and a sperm donor) and the other one with a donated egg and the intending father's (or donor's) sperm. In this scenario, the first zygote has faulty mitochondria and the second has healthy mitochondria. On the first day after fertilisation, the maternal and paternal pronuclei are removed from both zygotes. The enucleated cell produced with the intending mother's egg and the pronuclei which were housed in the cell produced with the donor's egg are discarded. Afterwards, the intending parents' (or intending mother's and donor's) pronuclei are ferried into the enucleated cell produced with the donor's egg. The reconstructed zygote, which possesses healthy mitochondria, can be subsequently transferred to the intending mother or a surrogate.<sup>9</sup>

In MST, eggs are obtained through ARTs from an intending mother and a healthy donor. The nuclear material from the intending mother's egg and the donor's egg is extracted. The donor's nuclear material and the intending mother's enucleated egg are discarded, and the intending mother's nuclear material is ferried into the now enucleated donor's egg.<sup>v</sup> Subsequently,

the reconstructed egg is fertilised in vitro and then transferred to the intending mother or a surrogate.<sup>6</sup> One of the aims of both techniques is for the donor's healthy mitochondria to help in the development of a healthy child and to be passed down via the maternal line to subsequent generations.

At present, approximately 30 mtDNA haplogroups in humans have been described.<sup>10</sup> The fact that there are so many groups is important for our discussion, as there is an ongoing debate regarding mito-nuclear interactions after MRTs. Some, for example Edward Morrow, argue that if the mitochondrial haplogroup of the egg donor is not matched to that of the intending mother this could give rise to mito-nuclear incompatibility, translating into adverse health effects for the future offspring.<sup>11</sup> The last report commissioned by the Human Fertilisation and Embryology Authority (HFEA) concerning MRTs being ready for clinical practice asserted that:

The panel continues to recommend that consideration is given to mtDNA haplogroup matching as a precautionary step in the process of selecting donors (...) At present, the panel believes any risks associated with a mtDNA-nuclear DNA mismatch remain theoretical; the recent studies examining embryonic cells and stem cells generated from MST-derived and PNT-derived human embryos reported no evidence of any complications or compromise of mitochondrial function arising from unmatched mtDNA haplogroups.<sup>12</sup>

Prior to the advent of MRTs, women at risk of transmitting an mtDNA disease who knew about their condition had the following options: first, refraining from having children; second, turning to adoption, embryo adoption or gamete donation; third, seeking to have genetically related children after undergoing oocyte sampling to assess the risk of recurrence (an option normally available to couples who have already had an affected child) or chorionic villus sampling or amniocentesis (and then deciding for or against termination) or by using PGD. It must be noted that while adoption, embryo adoption and gamete donation guarantee that future children will not be affected by an mtDNA disease, PGD and the other techniques do not always guarantee similar results.<sup>13</sup> For example, PGD is not effective when the mutations are novel or uncommon, and thus there are not enough reference clinical data available to guide the couple's decision.<sup>13</sup>

Different reproductive options are currently available for lesbian couples.<sup>14</sup> Some of them, such as adoption, embryo adoption and gamete donation, entail either refraining from having genetically related children (adoption and embryo adoption) or having children that are genetically related to only one of the couple (third-party reproduction). Recently, another possibility, ROPA (reception of oocytes from partner), has gained some visibility.<sup>15,16</sup> ROPA allows lesbian couples to have a child who is genetically related to one mother (ie, the mother who provides the oocytes which are subsequently fertilised with donor sperm) and who is gestationally related to the other mother. These options *do not allow* lesbian couples to have children who are genetically related to *both* of them.<sup>vi</sup> MRTs, on other hand, would

<sup>v</sup>Both for PNT and MST, if during the chromosomal transfer there is a large unintentional carryover of pathological mitochondria the mtDNA disease could manifest immediately afterwards and in subsequent generations.<sup>66,67</sup>

<sup>vi</sup>Even when it is true that there are epigenetic influences during pregnancy and that the gestating mother could be thought to have genetic ties to the child she bears, here we are using 'genetic' in a more narrow sense. We understand 'genes' as physical tokens of transmission that originate in the parent and that could be said to materially overlap between parent and child. We appreciate that there are many and important philosophical questions regarding the role of epigenetic influence in parenthood, but they are beyond the scope of this paper. We are indebted to one of the anonymous reviewers for pointing this out to us.



allow both women in a lesbian couple to share a genetic link with their offspring. Specifically, one of them would contribute with nuclear DNA and the other with mtDNA. Finally, it is important to mention that worldwide reproductive options for lesbian couples (and homosexual couples more generally) are often directly or indirectly limited by laws and regulations which restrict access to adoption and third-party reproduction.

### ARE MRTS THERAPEUTIC IN NATURE?

Debates on the ethics of reproductives technologies stir controversies as they touch on values and beliefs on the meaning of parenthood, the moral status of early human life and our obligations to future generations. In particular, debates on the ethics of introducing a new reproductive technology are characterised by reflections on the welfare of children born due to that technology. They are centred on the necessity of balancing uncertainties regarding the possible benefits and risks of such new technology and on the extent to which the reproductive freedom of prospective parents ought to be respected.<sup>17</sup> Even though competing moral views generate diverging assessments of the importance that should be granted to the values and beliefs at stake, concerns related to the welfare of future children are often considered more important than the reproductive freedom of prospective parents. This is so as preventing a child (although a future one) from suffering harm is considered a morally appropriate reason to restrict prospective parents' freedom.

Unsurprisingly, the debate on MRTs is no exception and welfare of the child considerations has been at the forefront of the ethical debate concerning these techniques. Interestingly, the welfare of children born due to MRTs has been employed *both as a critique of these techniques and as an argument in favour of them*. For instance, those who use the welfare of the future child to *oppose* MRTs maintain that these techniques are too risky for the health of future children, that their safety has not been thoroughly assessed, and that there may be unforeseen negative effects for the children conceived due to MRTs and for these children's children.<sup>18–23</sup> For example, Françoise Baylis asserts that:

Mitochondrial replacement technology is experimental and there is very limited information about safety and efficacy. As with any germline intervention, there are significant and legitimate concerns about the health and well-being of future children and the potential short-term and long-term harms to them and their progeny.<sup>18</sup>

According to this view, a concern for the welfare of future children (and those children's children) warrants banning or heavily restricting MRTs until all the above-mentioned worries have been dispelled. Interestingly, many of those in favour of the techniques have also appealed to welfare of the child considerations and maintain that it is such concerns which should motivate their approval, although their take on the present safety of the techniques is radically different.<sup>24–27</sup> According to such commentators, the severity of certain mtDNA conditions and their disabling and life-limiting character are sufficient reasons to allow for the clinical use of MRTs. For example, Arthur Caplan argues that an MRT procedure 'is not without its risks, but it's treating a disease'.<sup>28</sup> And that '[t]hese little embryos, these are people born with a disease, they can't make power. You're giving them a new battery. That's a therapy'.<sup>28</sup> Framed in this way, it is clear that MRTs can be regarded as a therapy for mtDNA diseases.

The argument in favour of MRTs based on their 'therapeutic' nature is a powerful one: who would dare object to the approval

of safe techniques that spare children from suffering? This argument runs something like this: we are morally required to prevent the suffering and premature death of innocent individuals. MRTs can prevent the suffering and premature death of existing innocent individuals. Hence, we are morally required to carry out MRTs.

The framing of MRTs in terms of a therapy for mtDNA diseases for existing individuals (in contrast with future ones) allows supporters of these techniques to build a moral case in favour of their approval and, at the same time, to raise a supposedly justified moral boundary. The moral line is drawn between uses that are therapeutic, and hence good, and uses that are 'beyond therapy', and hence morally suspicious. In order to make our case that lesbian couples should have access to MRTs to have genetically related children, we first challenge their alleged therapeutic nature. Doing so allows us to show that the therapeutic/non-therapeutic moral boundary does not exist and thus that criteria of access to MRTs must be grounded on other considerations.

Thus far, Wrigley *et al*<sup>27</sup> have carried out the most thorough defence of the therapeutic nature of MRTs (or at least of one of the two techniques). The authors maintain that 'PNT [...] is a form of therapy based on embryo modification while MST is, instead, an instance of selective reproduction'.<sup>27</sup> They draw this conclusion from the observation that the process of PNT (which entails enucleation, transfer and reconstitution) does not affect the numerical identity of the embryo as it already exists. PNT pre-emptively cures an already existing being. Conversely, at the point of the process of MST (which also entails enucleation, transfer and reconstitution), it is unknown (in almost all cases) which *sperm cell* will fertilise the reconstituted oocyte, and thus the identity of the future individual has not been determined (supposing that our numerical identity is determined by specific gametes which fuse). On this basis, Wrigley *et al* conclude that MST cannot cure anyone while PNT does. The upshot of their argument is that there 'is a strong prima facie harm-avoidance rationale for offering PNT to prospective parents and for those parents to accept it; one that is not present in the case of MST [emphasis added]'.<sup>27</sup>

Wrigley *et al*'s stance has been criticised for a number of reasons.<sup>29–30</sup> One point of contention is that there is no harm-avoidance rationale for offering PNT to prospective parents, as at the point of offering it there is no one who could be subject to PNT and thus no one who could be cured. When *the clinical decision to employ* PNT is made, it affects which sperm and egg will fuse, which means that: 'the gametes that will fuse in order for the process of PNT to happen *would most certainly not have fused* in the first place if PNT had not been chosen as the course of action'.<sup>29</sup> This is the case because after the decision to carry out PNT has been made, the woman will have to be subject to hormonal stimulation and to the egg extraction process. This means that the egg that would have been fertilised the month that she/the couple decided to undergo PNT is not the same egg as that which will be fertilised prior to undergoing the PNT procedure. And even in the rare case of having only one single cryopreserved egg, the sperm cell that will fertilise the egg will depend on when the sperm sample is provided or which sperm from an already collected sample is actively chosen or which sperm happens to fertilise the egg in vitro from an already collected sample. All this shows that *the clinical decision to employ* PNT affects the timing of conception and thus who will exist.

Additionally, Matthew Liao has argued from an Organism View account that *the process of MST and PNT* is numerically

identity-affecting.<sup>31</sup> According to Liao, the enucleation, transfer and reconstitution actions are of such nature that both eggs, or both embryos, cease to exist and a *third* egg, or embryo, is created. In order to understand Liao's argument, we must bear in mind that an egg, or embryo, is an organism. An organism, *as a kind of thing*: (1) begins to exist when the capacity to regulate and coordinate the various life processes (respiration, absorption, metabolism and so on) is there; (2) it persists as long as there is a continuing ability to regulate and coordinate the various life processes and (3) it ceases to exist when the capacity to regulate and coordinate the various life processes is permanently gone.<sup>31</sup> The two main reasons why the enucleation process permanently disrupts the organismic continuity processes of the eggs, or zygotes, are: first, that the cytoplasm of an egg, or zygote, contains crucial components for regulating and coordinating the various life processes; second, that there are life processes in the cytoplasm of an egg, or zygote, that the nucleus does not control (fully, at least).<sup>31</sup> What this means is that an egg's capacity to regulate its metabolism, for example, is destroyed when we enucleate it, and thus *a new capacity* comes into being when we transfer the intending mother's maternal spindle into the donor's enucleated egg. This metaphysical stance is relevant when morally assessing MRTs, as it follows from it that 'in essence' neither technique is therapeutic. They are not therapeutic because they *do not cure anyone*; they just bring into existence a new organism.

Furthermore, by maintaining that numerical identity follows the nuclear DNA, Wrigley *et al* appear to endorse the view that cells are essentially their nuclear genes (or a collection of them). But if *genes* are what establish numerical identity, then why is the mtDNA not part of what constitutes the numerical identity of a cell, as it also contains genes? Why consider only the nuclear genome and not that plus the mitochondrial one? And equally, why is it the case that *all* the chromosomes establish numerical identity and not only a subset of them? Wrigley *et al*'s view does not offer a compelling case of the notion that cells are essentially their nuclear genomes.

According to the previous arguments neither MST nor PNT are therapeutic and hence a moral case for them and, more importantly, for restricting their use cannot be based on how the welfare of a *particular* child will be improved. These considerations have two implications: on the one hand, it is necessary to abandon the rhetoric of cure and therapy and on the other that additional reasons should be presented to ground the moral case in favour of MRTs. Let us now consider another argument that could justify the moral acceptability of MRTs: reproductive freedom.

## REPRODUCTIVE FREEDOM AND MRTS

Those who have advocated the legalisation of MRTs in UK have frequently appealed to the importance of allowing couples at risk of transmitting an mtDNA disease, the freedom to choose to procreate according to their preferred life plan: what is commonly referred to as reproductive freedom or procreative liberty.<sup>vii32–35</sup> They argue that couples should be free to choose whether to have genetically related healthy children and that third parties—be them the state, religious institutions or fellow citizens—should not interfere with their choices. For example, Andrew Miller, the chair of UK's Commons Science and

Technology Committee from 2010 to 2015, argued against the lobbying efforts by religious groups to reject MRTs: 'It is utterly outrageous in a free society for the churches to tell parents who are in this painfully difficult position that they cannot undergo procedures like this'.<sup>36</sup> Why was Miller angered by the churches' interference in procreative decisions? In this section, we first try to make sense of Miller's (and other defenders of reproductive freedom) outrage, and we then show that if MRTs fall within the remit of the reproductive freedom of heterosexual couples where women are at risk of transmitting an mtDNA disease, then they also fall within the remit of the reproductive freedom of lesbian couples.

In contemporary Western democratic societies, freedom of choice is defended from third parties' interference on political and moral grounds. This has its roots in the work of John Stuart Mill and other liberal philosophers. Mill believed that the only appropriate moral ground for interference in one's actions is if one's free agency may cause *harm to others*.<sup>32 37</sup> In *On Liberty*, he asserts that there should only be 'one very simple principle, as entitled to govern absolutely the dealings of society with the individual in the way of compulsion and control'. The principle states that:

the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.<sup>37</sup>

The former is commonly known as Mill's 'Harm Principle', a principle that sits at the core of our liberal democratic societies, where, 'the presumption in favour of the freedom of citizens to make their own choices without interference places the burden of proof on attempts to limit freedom'.<sup>38</sup> Isaiah Berlin labelled this Millian understanding of freedom as *negative freedom* or *freedom from*.<sup>39</sup> Elements of this negative understanding of freedom survive in defences of the moral right of people to make 'autonomous choices in matters of procreation'<sup>40</sup> or, as John Robertson puts it: 'the freedom to reproduce or not to reproduce in the genetic sense'.<sup>33</sup> John Harris, John Robertson, Dan Brock and other contemporary advocates of reproductive freedom strongly emphasise the importance of defending the freedom of people to make significant choices in matters of procreation without third parties' interference. They also maintain that this procreative freedom ought to be limited only if it becomes incompatible with a like liberty for all or if it may cause significant harm to others. Harris' and Robertson's theorising of reproductive freedom only in negative terms has been criticised most notably by Catherine Mills, who argues that reproductive freedom also contains positive elements and who understands it as a 'practice of self-making', one that allow prospective parents to 'give shape' to their lives.<sup>38</sup> In this sense, reproductive freedom incorporates the negative elements of the Millian liberal tradition and some of the positive elements that Berlin also identified, those that allow for self-determination and that make our actions the product of our own agency.<sup>39</sup>

But why does reproductive freedom matter? Why is it a constant reference and point of contention in debates on assisted reproduction? Different authors have provided (slightly) different accounts of why reproductive freedom ought to be treated as a fundamental moral good, but at the core of all these accounts are two moral bases for its defence: the centrality of reproduction for the development of personal life plans (the autonomy argument for reproductive freedom) and for the well-being of individuals (the welfarist argument for reproductive freedom).

<sup>vii</sup> Here we do not distinguish between the different expressions used to refer to reproductive freedom (ie, reproductive autonomy and procreative liberty).

The autonomy argument grounding reproductive freedom refers to the morally relevant interest of individuals shaping their own lives according to the values or interests which are relevant to them.<sup>41 42</sup> Reproductive freedom is thus important not in itself but due to 'the values or interests or standing that this particular constraint defeats'.<sup>41</sup> Applied to the MRTs debate, the autonomy argument provides a sound moral defence of the right of couples at risk of transmitting an mtDNA disease to their children to reproduce as they want and to have healthy children that are genetically related to them. The welfarist argument, on the other hand, focuses on the relevance of reproductive decisions for individuals' well-being and understands reproduction as a 'core human activity'<sup>33</sup> or 'fundamental right'.<sup>43</sup> Failing to respect reproductive freedom and placing constraints on its exercise may negatively impact individuals' well-being and their ability to lead a good life.<sup>35</sup> It is for these reasons that reproductive freedom should not be interfered with for *trivial* reasons and that placing limits on reproductive freedom is morally acceptable only for significant reasons, such as the occurrence of significant harm to others.<sup>viii</sup>

When we take into consideration our previous discussion on the 'therapeutic' nature of MRTs, we realise that Mill's 'harm principle' does not relate to a consideration of the created child. What we are maintaining here is that under a personal account of morality and a counterfactual account of harm—if your act harms someone, then it makes that person worse off than they would have been had you not done the act<sup>44</sup>—neither PNT nor MST leave created children worse off than they would otherwise have been. Such children are not made worse off by MRTs because the only other available 'option' for them is not to exist.<sup>ix</sup>

Our premise that MRTs do not inflict harm to future children leads to the conclusion that these technologies fall, under a Millian understanding of freedom, within the proper remit of the reproductive freedom of women with mtDNA diseases. Given the moral importance of reproductive freedom for people's capacity to be autonomous and for their well-being, we can further argue that *the current UK legislation* on MRTs benefits women at risk of transmitting an mtDNA disease (and their partners). It benefits them as these techniques represent an additional reproductive option, one that allows them to have healthy genetically related children (if they wish to do so).<sup>x</sup> Then

<sup>viii</sup>For a discussion of the limits of reproductive freedom and of limits other than significant harm to others, see Dan Brock and Allen Buchanan *et al*, chapter six in particular.<sup>32 35</sup>

<sup>ix</sup>Two things must be clear: first, that the only case where someone could be harmed here is if their life is a wrongful one; second, that this is a classic instance of the Non-identity Problem. Expanding on the Non-identity Problem would require more space than is available here. For a compelling case of why children are not harmed, see David Boonin's work on this issue.<sup>44 68</sup>

<sup>x</sup>The idea that more choices lead to greater freedom and well-being has been challenged notably in the work of Gerald Dworkin, Nikolas Rose and Barbara Katz Rothman.<sup>69–71</sup> They have argued that more options can also have the effect of bringing about more perceived and actual responsibilities. Recently, one of us has further elaborated this view in the context of genome editing and assisted reproduction.<sup>17</sup> In the case of MRTs and couples at risk of transmitting an mtDNA disease, however, the range of (reproductive) options currently available includes either refraining from having offspring who are genetically related to both prospective parents or risking passing on the mtDNA disease. MRTs would allow the additional option of having healthy children who are genetically related to both prospective parents. Similarly, as shown above, the (reproductive) options currently available to lesbian couples do not allow them to enjoy genetic kinship. For these reasons, MRTs could not be said to count as a *mere quantitative* addition to the range of options currently available to prospective parents, but as a *qualitatively*

again, (explicitly) *legislating against* MRTs would violate these women's reproductive freedom by restricting their *significant* range of reproductive options and the possibility of enjoying genetic parenthood. The upshot of considering that the moral case in favour of these technologies is that they add a significant reproductive option to prospective parents is that the ethical focus shifts from mainly taking into account questions of the safety and welfare of future children to considering how these technologies have the potential to *benefit* prospective mothers and couples.

At this point, we have reached the crux of the issue: namely, the moral reasons for making MRTs available to women at risk of transmitting an mtDNA disease, *ceteris paribus*, also ground their access to lesbian couples as: (1) people have a great interest in reproduction because of how it shapes their lives according to the values and interests which are relevant to them, and it is also a very deep personal and private project which has a significant impact on individuals' well-being and (2) the fact that MRTs cannot be said to harm any child created through their use. Finally, the fact that lesbian couples need a sperm donor, in addition to their own eggs, does not detract from our stance. It does not do so as sperm donation for family-making purposes is morally acceptable.<sup>45</sup>

At this point, it would be possible to counter that mitochondria *only* produce energy and *only* represent 1% of the total amount of genetic material, and thus that lesbian couples opting for them would just be embarking on a very expensive vanity project. Explaining in detail why these claims, which John Appleby<sup>46</sup> has named the 'qualitative claim' and the 'quantitative claim', are problematic for arguing that MRTs cannot establish parenthood would require much more space than we have available here.<sup>47</sup> What we can state is that, following our previous section on how MRTs affect numerical identity, in the case of a lesbian couple both mothers would be parents under a causal account of parenthood, at least. They would be so because: 'any [free] action that reasonably foreseeably results in the birth of a child generates responsibilities for that child'.<sup>48</sup> And in this case, their free action of seeking MRTs, and the subsequent assisted reproductive steps, reasonably foreseeably results in the birth of a child.

## REPRODUCTIVE FREEDOM AND TREATING LIKE CASES ALIKE

The possible use of MRTs as a reproductive option by lesbian couples has already been mentioned in the bioethics literature by the Nuffield Council on Bioethics, Françoise Baylis, Palacios *et al*, Rebecca Dimond, Ishii and Segers *et al*.<sup>18 49–54</sup> Furthermore, from a legal point of view, Danielle Griffiths has explored how UK regulations on MRTs reproduces the heteronormative genetic family.<sup>55</sup>

However, in such literature, this possible application of MRTs is typically mentioned only in passing. A notable exception is Françoise Baylis. In her article 'The ethics of creating children with three genetic parents' she lists this possible use of MRTs under the heading 'Harms to society'. She asserts:

While the initial goal of mitochondrial replacement technology is 'therapeutic' insofar as it aims to avoid the birth of a child with mitochondrial disease, this technology could be used without therapeutic intent. For example, it could be used to pursue non-therapeutic reproductive goals—imagine, a lesbian couple where

*significant* new option. We are indebted to an anonymous reviewer for bringing this point to our attention.



both partners wanted a genetic link to the children they intend to parent.<sup>18</sup>

Why the use of MRTs by lesbian couples would be harmful to society remains unclear in her article. With some exercise of imagination, and assuming that she in fact believes so, it seems that such harm stems from the fact that this use of MRTs would not be 'therapeutic', understanding therapeutic in the sense that 'it aims to avoid the birth of a child with mitochondrial disease'.<sup>18</sup> Non-therapeutic uses of technologies have been frequently condemned by bioethics scholars because they may corrupt values that we cherish<sup>2</sup>; they may damage our relationships among members of a society of equals<sup>1</sup> and they may be instances of eugenics.<sup>56</sup> However, despite Baylis' concerns, morality demands treating like cases alike: if we accept that the use of MRTs by women at risk of transmitting an mtDNA disease neither harms society because a child without a mitochondrial disease would be created nor spares any individual from suffering, then we have to accept that the use of MRTs by lesbian couples does not harm society, because a child without a mitochondrial disease would be created, nor spares any individual from suffering. It is true that both types of uses could be considered 'eugenic', rather than 'therapeutic', in the sense that they aim to bring a particular kind of individual into existence: healthy people who are genetically related to their parents. It is for the above-mentioned reasons that we find Baylis' position wanting. All the more so, denying access to MRTs to lesbian couples is ethically unjustifiable in as much as it curtails the enjoyment of certain freedoms to a certain group without good reason, while allowing others to enjoy the very same freedoms. Those who want to prohibit the use of MRTs by lesbian couples need to present an argument for showing that them obtaining access to this technology is unethical, an argument that so far no one has successfully presented.<sup>x1</sup>

### GENETIC RELATEDNESS AND MRTS

Let us take stock of what we have argued thus far. We have presented some arguments against the view that MRTs are *therapeutic* technologies and hence concluded that concerns for the welfare of the future child cannot ground their moral acceptability nor restrict their use. We have then focused on the other reason that may morally justify offering MRTs, namely the reproductive freedom of prospective parents. We have argued, *contra* the position of those who want to restrict use of MRTs only to women at risk of transmitting mtDNA diseases, that morality demands treating like cases alike; and we maintain that a concern for equality would deem immoral a restriction on the use of MRTs based on one's belonging to a group with certain sexual preferences. In this final section, we consider a potential objection to our argument: namely that the desire for genetic relatedness is not a morally sufficient reason to allow lesbian couples to access MRTs.

<sup>x1</sup>At this point, someone might claim that the possibility of mitochondrial incompatibility speaks against the use of MRTs by lesbian couples. We can reply to this challenge in the following way: first, there can be lesbian couples where both women belong to the same haplogroup, and thus even if such interaction-worries materialise for them, they would not be a problem. Second, at this point in time, as the HFEA report mentions, such putative problems are theoretical, and even if they were to materialise lesbian couples should still have the option of resorting to MRTs (unless the created lives were wrongful ones). This position is not a radical one, but just the same as that which postulates that couples should be able to resort to assisted reproduction even when they know that their children might be at an elevated risk of having a disability.

One of the criticisms against MRTs, and against other reproductive technologies, is that their sole benefit is to allow parents to have a genetic tie to their offspring, which is considered a morally dubious end.<sup>57</sup> In this section, we refer to this as the genetic-relatedness objection (GRO) to MRTs. Underlying the GRO are two distinct types of concerns, one inspired by deontological concerns and the other inspired by consequentialist concerns. Deontological concerns (GRO-d) centre on the morally dubious character of those seeking genetic relatedness. This desire is suspect, critics argue, because it expresses a non-virtuous parenting attitude, one that aims at having *particular kinds* of children, which is considered by critics 'a wish and not a need'.<sup>2 18</sup> We do not explore further the GRO-d, as others have done so.<sup>58</sup> Other concerns underlying the GRO are consequentialist in nature (GRO-c). GRO-c focuses on the negative consequences which allowing prospective parents to use MRTs (and other ARTs) may generate. The negative consequences identified by the critics include: concerns for the resources needed to develop new technologies and how these resources may be employed for other more pressing medical needs<sup>18 57</sup>; the reinforcement of ideas on the importance of genetic kinship for family-making and on the role of genetics more generally to determine our identities<sup>57 59</sup>; the medicalisation of a social preference<sup>57 59</sup> and the reinforcement of the two-parent (heterosexual) genetically based model of the family (ie, bionormative conception of the family).<sup>19</sup>

At first sight, the initial type of GRO-c concerns, those hinging on the scarcity of available resources, seems to be legitimate. In practical terms, what this concern means is that, when we argue about the moral permissibility of MRTs, we have to factor in the costs of *satisfying this preference*, even if it is a strongly held one, against other medical opportunity costs, for example *satisfying the basic medical needs of others*. According to Baylis, once faced with this choice we have to reach the conclusion that research and clinical practice on MRTs are immoral. They are immoral given that they use scarce medical resources that could be better used elsewhere, because, as noted by Rulli and others, the development of MRTs requires(-ed) the use of vast resources both in terms of budget and personnel.<sup>57</sup> One way to respond to this objection is to note that even if we grant Rulli's and Baylis' point regarding the use of scarce medical resources, from this fact it *does not inherently follow* that the use of medical scarce resources for MRTs is immoral. This is because in order to make such a claim, we need to prove that when compared against all other medical research that is being carried out the use of scarce medical resources for MRTs is unwarranted.<sup>60</sup> Our concern here is *not* to examine the ethical case in favour of or against MRTs nor to provide an account of the ethical issues surrounding these techniques, but rather to stress the need to *extend the existing criteria of access to these techniques to lesbian couples*. Furthermore, concerns related to the necessary clinical research to develop MRTs do not apply in the case of lesbian couples, as these techniques are already in place; and in fact the use of MRTs by lesbian couples, and possibly by other non-mtDNA infertile couples, should be factored in when considering the overall offsetting of the costs of this research.

Last, we consider GRO-c concerns related to the reinforcement of genetic deterministic ideas about the importance of genetic relatedness for family-making and the reinforcement of the bionormative family. Many women and couples have a strong preference for having genetically related children.<sup>xii61</sup> This is true for both women

<sup>xii</sup>One may dispute, as previously stated, that MRTs allow couples at risk of transmitting an mtDNA disease and lesbian couples to achieve

with mtDNA diseases and lesbian couples, and we contend that in a liberal society allowing only heterosexual couples to enjoy the satisfaction of their wish, regardless of its philosophical validity, is problematic from the point of view of equality. This is akin to only allowing certain ethnic groups to access assisted reproductive technologies, for example.

In addition, gay and lesbian couples' reproductive choices are already limited: depending on the countries' regulations, these couples are often ineligible for third-party reproduction and for adoption. Preventing them from using an already existing technology due to consequentialist concerns related to the reinforcement of genetic determinist ideas on the value of genetic relatedness seems to us akin to further restricting their already limited agency with respect to reproductive options.<sup>xiii</sup> Hence, even though it is true that we should be attentive to the fact that MRTs could contribute to increasing the value attributed to genetic relatedness, to the detriment of other forms of family-making, it must be said that it would be morally problematic to just focus on lesbian couples and their wishes and choices thereof. In other words, we believe that it is compatible to hold the view that reproductive technologies such as MRTs might have undesirable consequences such as the ones described by the critics of these technologies, and the view that genetic relatedness seems to be an important good whose enjoyment should not be restricted on an arbitrary basis.

Regarding GRO-c concerns for the preservation of the bionormative family, it must be noted that in the case of MRTs being used by lesbian couples, this charge does not apply. The use of MRTs by lesbian couples in fact defies the current dominion of the bionormative family in that it challenges the *folk assumption* about the *correct type and amount* of shared genes that are necessary for establishing a parental genetic link—50% of the nuclear genes from the father and 50% of the nuclear genes from the mother.<sup>xiv,47</sup> Specifically, what it is asserted here is that 1% of an mtDNA genetic connection *suffices* for establishing genetic parenthood.<sup>xv</sup> Even more so, regulating MRTs so as to include lesbian couples

the same end, namely to have genetically related children. While for the first group of couples MRTs allow them to have children whose genetic make-up contains genetic information from both nuclei of the parents, for lesbian couples the situation is different as one party of the couple would provide the nuclear DNA and the other would provide the mitochondrial DNA. The *sociological* question of whether contributing with 'merely' the mtDNA would be sufficient for lesbian couples to regard the children born thanks to the aid of MRTs *as their own* is yet to be answered. However, we maintain that the legislature should not a priori rule against this, based on the idea that mtDNA contributes less to genetic kinship than nuclear DNA.

<sup>xiii</sup>From *The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015*, it is not at all clear if in UK MRTs can only be accessed by heterosexual couples, or if lesbian couples could access them if one of the intending genetic parents is at risk of passing on a serious form of mtDNA disease.

<sup>xiv</sup>It must be noted that in the *reproductive cloning debate*, some authors already acknowledge the possibility of becoming a genetic parent through mtDNA. Mary Mahowald, for example, asserted that 'through use of one woman's nuclear DNA and another woman's enucleated egg, a lesbian couple may have a child who is biologically related to both without requiring sperm donation' and that 'the ovum in which that parent's DNA is inserted represents a significant environmental influence on development, and the mitochondrial DNA adds a genetic component to the environment of the nuclear DNA'.<sup>72</sup> Others who have commented on this issue are Jean Chambers, Timothy Murphy and Carson Strong.<sup>73–76</sup>

<sup>xv</sup>It must be noted that this claim aims at subverting the *folk western conception of genetic parenthood*, and that it is not a claim regarding the metaphysics of reproduction. For an account of why MRT-conceived children do have three genetic parents, see Monika Piotrowska's *Is 'Assisted Reproduction' Reproduction?*.<sup>77</sup>

would expand the models of *state-recognised* genetic relatedness and challenge the existing order and, as seen by Griffiths, not doing so would be 'an example of how science and regulation seek to expand models of traditional relatedness in a way that does not challenge the (bionormative) existing order'.<sup>55</sup>

## CONCLUSION

In this paper, we have challenged the view that MRTs are a therapy for mitochondrial diseases, and that these techniques can be considered harmful to children. We have argued that the rationale for offering these techniques must lie somewhere else, namely within concerns for the reproductive freedom of prospective parents. Shifting the focus of the moral debate on MRTs from concerns for the welfare of the children to other moral justifications for offering MRTs allows for the emergence of other questions that require moral consideration. In particular, it allows us to consider how an unduly restrictive approach to accessing MRTs to a particular group requires arguments that have not been presented thus far. We do not want to defend here the wish for genetic kinship as an absolute good that trumps other considerations and nor do we believe that reinforcing a family-making process that includes a genetic element is without costs. However, we remain convinced that these considerations cannot be employed solely to bar access to MRTs by lesbian couples, a group with an already limited range of reproductive options, as this would be immoral from an equality standpoint.

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## 5 Appendix 5

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DEBATE

Open Access



# A 14-day limit for bioethics: the debate over human embryo research

Giulia Cavaliere

## Abstract

**Background:** This article explores the reasons in favour of revising and extending the current 14-day statutory limit to maintaining human embryos in culture. This limit is enshrined in law in over a dozen countries, including the United Kingdom. In two recently published studies (2016), scientists have shown that embryos can be sustained in vitro for about 13 days after fertilisation. Positive reactions to these results have gone hand in hand with calls for revising the 14-day rule, which only allows embryo research until the 14th day after fertilisation.

**Main text:** The article explores the most prominent arguments in favour of and against the extension of the 14-day limit for conducting research on human embryos. It situates these arguments within the history of the 14-day limit. I start by discussing the history of the 14-day limit in the United Kingdom and the reasons behind the decision to opt for a compromise between competing moral views. I then analyse the arguments that those who are generally in favour of embryo research put forward in support of extending the 14-day rule, namely (a) the argument of the beneficence of research and (b) the argument of technical feasibility (further explained in the article). I then show how these two arguments played a role in the recent approval of two novel techniques for the replacement of faulty mitochondrial DNA in the United Kingdom. Despite the popularity and widespread use of these arguments, I argue that they are ultimately problematic and should not be straightforwardly accepted (i.e. accepted without further scrutiny). I end by making a case for respecting value pluralism in the context of embryo research, and I present two reasons in favour of respecting value pluralism: the argument of public trust and the argument of democracy.

**Conclusion:** I argue that 14-day limit for embryo research is not a valuable tool despite being a solution of compromise, but rather because of it. The importance of respecting value pluralism (and of respecting different views on embryo research) needs to be considered in any evaluation concerning a potential change to the 14-day rule.

**Keywords:** Embryo research, Value pluralism, Compromise, Beneficence, Warnock report

## Background

In August 2016, in a letter in *Nature* and in an article published in *Nature Cell Biology*, two groups based in different research centres in the United Kingdom (Cambridge and London) and in the United States (The Rockefeller University, New York) presented the results of their experiments on in vitro human embryos. For the first time, the embryos were sustained in vitro for 12–13 days after fertilisation [1, 2]. Prior to this, scientists were only able to sustain embryos in vitro for about seven days [3].

Many members of the scientific and bioethics communities reacted enthusiastically to these advances, due to the

novelty of the results and to the potential benefits that they could bring about [3–5]. Research involving human embryos allows us to increase our understanding of the first stages of embryo development and it is considered instrumental to shedding light on the causes of early miscarriages, of problems related to infertility and of birth defects [6]. In addition to this, embryo research has been instrumental to the development of human embryonic stem cells, cells derived from embryos have proved to be clinically useful to cure certain degenerative diseases [6–8]. Sustaining embryos in vitro for a longer period of time could allow an even greater understanding of the causes of embryo defects and early miscarriages, and it could prove especially clinically beneficial for women who have experienced multiple early pregnancy losses. Due to the current benefits of

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embryo research and to the potential future benefits of it, the positive reactions to these experiments went hand in hand with a call for revising and extending the so-called 14-day rule. This rule allows research involving human embryos up until the 14th day after fertilisation, a statutory binding limit in over a dozen countries [3, 9].

This article explores the arguments for and against extending the 14-day limit for research on human embryos. In the following section, I briefly present the history of how the 14-day rule came about in the United Kingdom and the reasons behind the decision to opt for a solution of compromise. In section 3, I discuss the arguments that those who are generally in favour of embryo research put forward in support of extending the 14-day rule, namely the argument of the beneficence of research and the argument of technical feasibility (further explained below). I show how these two arguments played a role in the process that led to the approval of mitochondrial replacement techniques in the United Kingdom. In section 4, I discuss why I find these arguments wanting. In the last section (5), I present two arguments in favour of compromise, namely the argument of trust and the argument of respect for value pluralism. I conclude that the importance of respecting value pluralism needs to be taken into account in any evaluation concerning a potential change of the 14-day rule.

### The 14-day limit and the Warnock report

The publication of the aforementioned two articles in *Nature* and *Nature Cell Biology* triggered a resurgence of the debate on embryo research and on the 14-day limit to carry out research on in-vitro human embryos. The 14-day limit came about in the United Kingdom at the beginning of the 1980s. Its birth is closely linked to another, non-metaphorical, British birth: the first test-tube baby (i.e. a baby conceived via in-vitro fertilisation), Louise Brown, was born in the United Kingdom in 1978. As noted by historian Duncan Wilson, after the initial excitement surrounding Louise Brown's birth, public attitudes towards IVF shifted from an initially more favourable stance to a more critical view of the practice [10–12]. These predominantly negative attitudes, and the necessity to decide upon the fate of embryos 'left over' after IVF procedures,<sup>1</sup> contributed to calls for a tighter oversight of the practice. They also underscored the importance of deciding whether it was permissible to use these spare embryos for research [10–12].

At that time, embryo research was the most debated matter concerning the ethics of IVF [13–15]. Two conflicting positions dominated the public debate: on the one hand, those of whom were outright against embryo research. On the other, those of whom were in favour of doing research on embryos up until it was technically feasible. The first group appealed to the need to respect

human life from its very beginning and argued that life starts in the moment of fertilisation (i.e. when sperm cells fertilise oocytes) and must be protected. Interestingly, not all the opponents of embryo research holding the view that embryos are persons were arguing from a religious standpoint [15]. Some of those arguing against embryo research in principle referred to the potentiality of the embryos to become fully developed persons and concluded that human life, no matter at what stage of development, should be granted full protection, and that embryos should not be used for research [16–18]. The opposing view, held by those in favour of legalising embryo research, found support from those appealing to the potential benefits of such research, and from those who granted inexistent or low moral status to the embryos. This group also referred to the potentiality of embryos to become fully developed persons, but concluded that potential persons (i.e. embryos) were different from actual persons and that this was a sufficient reason to allow research on human embryos [13]. Unsurprisingly, according to them, the potential benefits of such research, for instance an increased understanding of early human development, better IVF procedures and treating infertility and pregnancy losses outweighed the costs of embryo research [13].

There are some differences between the 1980s debate on embryo research and today's newly emerged debate. Perhaps, the main difference is that, whereas previously research beyond the 14-day mark was scientifically untenable, it has recently become technically possible. When the limit was decided upon, scientists were not able to keep the embryos alive in vitro for longer than the limit allowed. The experiments reported in the two recent articles prove that scientists are now able to keep embryos alive for up to 12–13 days and possibly longer. In addition, IVF as an assisted reproductive technique has significantly improved and many of the technical advances in this technique are owed to embryo research. It is in this sense that, while the 1980s debate focused on the question of whether embryo research should be allowed, the current debate occurs against the backdrop of the advances that allow embryo research to be made possible. Moreover, while in the past it was not possible to preserve the viability of the embryos employed for research, today there are technical solutions that allow scientists to obtain embryonic stem cells for research that do not result in the destruction of the embryo (e.g. embryo biopsy<sup>2</sup>). Lastly, whilst previous research was carried out on early human embryos only, today, and potentially increasingly in the future, embryo research could be done on artificial entities that bear sufficient resemblance to embryos to be suitable for such research. To name a few methods, these entities would be created through, for instance, altered nuclear transfer (ANT) or parthenogenesis of oocytes [6, 7, 19].<sup>3</sup>

### Conflicting moral views on embryo research

Today's discourses on the moral status of human embryos are not so different from the discourses that, in the 1980s, resulted in the establishment of the *IVF Inquiry*, a committee appointed to produce an advisory report on the moral, legal and social issues raised by IVF, embryo research and other practices. Oxbridge philosopher Mary Warnock was appointed its chair. As I show in the next sections, the procedural work of the committee, the views of the chair, and the way the recommendations on how to proceed about embryo research were drafted represent an important precedent for the current debate on embryo research.

The members of the committee, including Warnock herself, were aware of the conflicting moral views on embryo research, and of the difficulty of reconciling them and establishing which one should prevail [20–22]. In addition to this, they tried to review as many different points of view as possible: the committee considered evidence from experts working in the field of human reproduction (around 300 individuals and organisations) as well as from the public (695 letters and submissions). Although the evidence collected in this way was never published<sup>4</sup> and although it was never made transparent how this evidence influenced the final recommendations, it is presumed that the committee considered all the submitted evidence and took into account the different views that it reflected [15].

Legitimising embryo research would have likely caused uproar from those who accorded full moral status to human embryos. At the same time, an outright ban on embryo research was perceived as problematic for two reasons: due to a concern for the loss of potential benefits of embryo research, and due to the perceived need to allow IVF to go forward only if backed up by studies on the development of early human embryos. A solution to this impasse was to find a compromise between these two positions: this is how the idea to introduce a cut-off point until which research would be permissible came about. Introducing a cut-off was a solution of compromise, as it would have enabled embryo research, but only until a certain stage of development. Different possible limits were examined, including the 5th day (i.e. beginning of implantation in utero) and the 11th day (i.e. the end of implantation) after fertilisation.

It was developmental biologist Anne McLaren, a member of the committee, who proposed using a peculiar biological event in the embryo development to mark the end of the permitted period of research [11]. McLaren suggested limiting research to the 14th day of development because this moment signals the emergence of the primitive streak in the human embryo, a precursor of the brain and the spinal cord. At the same time, the emergence of this streak marks the beginning of gastrulation, a process whereby the

embryonic inner cell mass starts to differentiate into three layers (endoderm, mesoderm, and ectoderm). This process also corresponds to the last point in which the embryo could cleave into twins (i.e. twinning) or in which two embryos could merge into one (e.g. tetragametic chimerism). McLaren argued that: "If I had to point to a stage and say 'This is when I began being me', I would think it would have to be here" [23]. In order to endorse the 14-day limit and the decision to allow research up until this stage of embryo development, the term 'pre-embryo' was coined. It designated the embryo before the emergence of the primitive streak, and it marked a distinction from the 'unborn child' (i.e. the embryo after the 14-day) [12, 23]. It was therefore a term with ethical and political significance, a term that designated the boundary between acceptable and non-acceptable research.

Eventually, in 1990, the recommendations of the IVF-Inquiry comprised in the Warnock Report [21] were enshrined into law, in what became the Human Embryology Act [22].

### How the 14-day limit came about: Compromise and its critics

Introducing a cut-off date –in this case the 14-day limit – represented an instance of favouring compromise between competing moral views, beliefs and values over questions of rightness and wrongness [10, 15, 24]. Questions regarding whether or not the embryo has moral status, what moral status stands for and entails, and questions regarding the core features of personhood and the beginning of human life were overridden by other considerations. These considerations included the moment from which the embryo should be granted legal protection, what kind of society can be praised and in what kind of society people can live with clear conscience [12, 14]. The decision to shift the focus from ontological questions concerning rightness and wrongness to more practical questions is linked to a conception of morality whose role is to address moral matters arising in the context of public policy. The IVF-Inquiry was not created to produce perfect philosophical reasoning and give a lesson in moral expertise, but rather to facilitate a process whereby scientists' work would become more "socially palatable" and whereby workable regulations would be delivered [12, 25].

The committee favoured a moral relativistic approach to embryo research and to the conflicting positions present in the debate. Instead of trying to establish which position was the most accurate one and what view came closest to an absolute moral truth, the committee worked under the assumption that the views of those for and against embryo research deserved to be equally respected and taken into consideration. Thus, the view of those who believed that the embryos are to be treated as if they were persons (and

hence, they deserve full moral status) and research on them should be banned, and the view of those who believed that embryos are not more than a cluster of cells (no moral status at all) and research on them should go forward were equally taken into account. In this sense, the committee followed the assumption that the truth and standing of moral judgments is not universal, but relative to the social, political and cultural context in which these moral judgements arise [26]. Warnock and her committee experienced first-hand the diversity of views both in her committee and in society at large. Their strategy was to exercise tolerance in matters of morality and moral disagreement, and to respect value pluralism [14, 27]. Warnock understood the role of her committee in these terms: starting from the acknowledgement of the different and competing moral positions, she tried to find the path of greater social consensus among them [10]. In addition to this, Warnock and her committee opted to take into account not only moral arguments based on scientific evidence and philosophical reasoning, but also moral feelings and beliefs [18]. In this sense, they followed Hume's idea that feelings, and not pure calculating rationality, need to be considered in the assessment of ethical dilemmas and that morality is 'more properly felt than reasoned' [28, 29].

Perhaps unsurprisingly, given the existing disagreement on the matter, the committee recommendation to allow embryo research up until the 14th day was highly criticised. Three committee members were outright against embryo research and refused to endorse the final recommendations concerning this matter [15, 21]. Members of the conservative party, of the pro-life group LIFE and Christian scientists such as Ian Donald, publicly criticised the decision and lobbied against the report recommendation during the parliamentary debate on the matter [12, 15]. Generally, reactions from the more conservative side of the debate opposed this solution because it employed a sort of utilitarian calculus (i.e. the potential benefits of embryo research) instead of foregrounding considerations concerning how we ought to treat unborn persons.

Interestingly, both those against and in favour of conducting research on human embryos agreed on some of the reasons why the 14-day limit was at least problematic, if not completely wrong, namely arbitrariness and dodging the most fundamental question. Those that criticised the decision on the grounds of its arbitrariness argued that it was impossible to draw a morally and legally significant distinction between an embryo that was 13, 14 or 15 days old. However, supporters and critics of embryo research drew different conclusions from this impossibility to draw morally consistent lines: supporters argued that embryo research should have been allowed until it was technically feasible (i.e. until when the scientists could keep the embryo alive in vitro), while critics argued

that embryo research should have been banned altogether. Another point of convergence between supporters and critics was the fact that Warnock and her committee did not address the questions of when life begins and when an embryo becomes a person. The decision to focus instead on the legal and moral rights of the embryo, without addressing the issue of what an embryo really is, was seen as extremely problematic by both sides. According to them, it was impossible to decide whether or not the human embryo deserved protection without establishing why it/she/he deserved protection, in other words whether or not the embryo was a person [13, 18].

In addition to these critiques, philosopher John Harris criticised Warnock and the committee for taking into account people's feelings. Harris argued that not all feelings were moral feelings and not all of them deserved respect. According to him, moral feelings should be evaluated on their capacity to make the world a better place, to save lives and postpone deaths [13].

These reactions are important because they show that, back then as today, there is indeed a fundamental moral disagreement concerning early human life, how to treat human embryos and about the legitimate role of feelings and passions in public and regulatory discourses [30]. The reactions that followed the committee's recommendations show the extent to which these views were in fact incompatible. However, it is important to note that those who criticised the decision on the grounds of arbitrariness and inconsistency in a certain sense missed the point of the role and function of the committee. The committee was put together in the first place in order to maintain public trust and be a reliable means for external oversight of scientific research. For this reason, the recommendations were meant to be a solution of compromise rather than a means to find the most consistent moral view.

In the next section, I briefly outline the reasons that advocates of embryo research currently put forward in favour of extending the limit, and show how these same reasons have played an important role in the debate on whether to introduce two new techniques into the clinic.

### The reasons in favour of extending the limit

Scientists (Robin Lovell-Badge and Azim Surani quoted in [4]) and ethicists [3, 5] reacted to the results reported on *Nature* and *Nature Cell Biology* by publicly calling for an extension of the 14-day limit and for revising the current regulation of embryo research. The argument that they used strikes familiar chords: embryo research is beneficial and now technically possible, therefore it should be allowed. The two publications in *Nature* and *Nature Cell Biology* [1, 2] partially changed the narrative of the debate on embryo research: whereas in the 1980s it was a matter of legalising such research, today the debate is about



extending the 14-day limit for reasons grounded in beneficence and technical feasibility, and thus merely adjusting the regulatory framework of an already legalised practice. These reasons draw upon consequentialist premises and the principle of utility. They imply that being able to carry out potentially beneficial research and not doing so would be morally impermissible.<sup>5</sup>

According to the advocates of embryo research, the reasons in favour of extending the 14-day limit are stronger today than they were in the past. In 1984, these reasons relied on positive provisions of the potential benefits (i.e. the beneficence of research) and positive provisions of the future feasibility (i.e. technical feasibility). In the past, it was about faith in science and managing the uncertainties of potential future benefits of embryo research with certain regulations. Today, Harris, Lovell-Badge and Surani argued, it is about certainties concerning the benefits and certainties of technical feasibility: embryo research has proven to be both beneficial and feasible [4, 5].

The use of beneficence and feasibility in the debate on technical innovations recalls another debate where similar arguments have been advanced in response to scientific breakthroughs. Early in 2015, the United Kingdom became the first country in the world to allow two novel techniques that allow women with mitochondrial DNA diseases to have genetically related children with a decreased risk of developing mitochondrial diseases. Mutations in the mitochondrial DNA are the cause of many diseases including, for instance, mitochondrial myopathy, Leigh disease and diabetes mellitus, and they are normally inherited through the maternal line [31]. Up until the approval of these two techniques, prospective mothers needed to turn to oocytes donors, PGD or adoption in order to have children free from these genetically inherited mutations [32]. Although these techniques (maternal spindle transfer, MST, and pronuclear DNA transfer, PNT) have been depicted as involving the ‘replacement’ of the affected mitochondrial DNA of the oocyte of the prospective mother or of the fertilised oocyte with the mitochondrial DNA of a female donor, this description is inaccurate. What really happens is that the oocyte’s, or zygote’s, nucleus previously housed in a cell with deleterious mitochondria is rehoused in an enucleated cell with healthy mitochondria. The embryo that results from these techniques will have the genetic makeup of the prospective father, the mitochondrial DNA of a donor and the nuclear DNA of the prospective mother.

Despite the similarities between the arguments in favour of the extension of the 14-day limit and the arguments in favour of allowing mitochondrial replacement techniques (MRTs), it is important to note that there are differences between the current debate on extending the limit for embryo research and the recent debate on

MRTs.<sup>6</sup> These differences concern both the *content* of these debates (i.e. the specific arguments in favour and against and the object of the controversy) and their potential *outcomes* (i.e. extending an existing limit for embryo research instead of allowing two new techniques to be introduced into the clinic). With respect to the content, the arguments against MRTs focused on concerns regarding the implementation of newly developed techniques and the risks that their implementation may pose to future children. On the contrary, the arguments against the extension of the 14-day limit focused on basic research rather than clinical implementation. In particular, they pertain to the ethics of using intrinsically valuable beings such as human embryos for instrumental purposes. In addition, these debates differ in terms of what proponents and opponents wanted to achieve (i.e. in terms of outcome). The potential outcome of the debate on MRTs was to establish whether these new techniques were sound from a technical and moral point of view. On the contrary, the debate on embryo research is about setting a new limit for continuing existing research and for possibly gaining new insights into embryo development. These are just a few of the differences between the two debates and a detailed analysis of such differences is beyond the scope of this article. However, it is important to note that despite these differences, some similarities with respect to the argument in favour of MRTs and embryo research can be drawn. In particular, those in favour of MRTs and of extending the 14-day limit appealed to beneficence and technical feasibility arguments in both instances.

One of the most contested issues concerning the ethics of MRTs is whether these techniques would bring about changes to the human germline (i.e. changes in human oocytes, sperm cells or embryos that do not only appear in the children resulting from the procedure, but also in succeeding generations) [33]. Ethicists and scientists are divided over whether MRTs amount to germline modifications as changes introduced in the oocyte (in the case of MST) or in the zygote (in the case of PNT) concern the mitochondrial rather than the nuclear DNA [34]. In addition, as mitochondrial DNA is inherited from the maternal line, if only male embryos are transferred in utero, the modifications introduced with MRTs will not be present in the succeeding generations<sup>7</sup> [35]. An assessment of these arguments is beyond the scope of this article,<sup>8</sup> but what matters for the present analysis is that up until the approval of these techniques, modifications of the genetic makeup of sperm cells, eggs and embryos were only legally possible *in-vitro* and never for clinical purposes *in-vivo*. Modification of the human germline (i.e. gametes, and embryos) has traditionally been considered a line that should not be crossed. This line was recognised as morally relevant in 1978 with the

publication of *Splicing Life*, a report of the US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research appointed to regulate gene therapies, the reasons given were partly scientific (i.e. it was not technically feasible) and partly moral (i.e. it was seen as immoral to introduce changes that would have been inherited by future generations) [36, 37]. Modifying the human germline is seen as problematic because of the unforeseen effects on future generations, the risk of engaging in a form of new eugenics, the risk of sliding down a slippery slope to human enhancement, and other similar arguments [38–40]. These arguments were already put forward at the very early developments of gene therapy and rehearsed in recent debates on MRTs and gene editing [34]. However, both historically and more recently they have not remained unchallenged. Questions related to eugenics, enhancement and unforeseen effects on future generations have been widely discussed during the months prior to the approval of MRTs and they are still a matter of ethical inquiry, as shown by the increasing number of articles and reviews that address these issues [41–44]. In addition, the public consultation (2012) and the extensive reviews of the scientific methods of MRTs carried out by the HFEA (respectively in 2016, 2014, 2013, 2011), the work of the Nuffield Council<sup>9</sup> [44] and the parliamentary debate on these techniques have considered such concerns. The 2015 approval of these techniques by the UK Parliament could be seen as a first instance of crossing an internationally recognised ethical and legal limit due to reasons of beneficence (i.e. children born with these techniques will be free from mitochondrial diseases), but also due to the technical feasibility of germline modifications (prior to the parliamentary vote on MRTs, these techniques were not considered safe enough to be introduced into the clinic) [45]. It is in this sense that the sum of the arguments in favour of extending the 14-day limit echoes, albeit only partially, those in favour of allowing MRTs. Mitochondrial replacement techniques represent an interesting case study and set an important precedent for the ethical assessment of technical innovation. In contrast with other instances of internationally recognised bans such as the ban on human cloning, the approval of MRTs shows that longstanding limits such as the ban on germline modifications can be redefined once scientific advances make it possible. The argument of beneficence to allow research on human embryos for longer than 14 days is the same as the one made in the 1980s. What has changed is that while before it was technically difficult to introduce changes in reproductive cells and embryos that would be inherited by future generations,

and to keep the embryos alive in vitro for a longer time span, now both actions are theoretically possible. The question, therefore, is whether the potential benefits of embryo research and the feasibility of keeping the embryos alive for longer than ever before are sufficient reasons to extend the limit.

### **There is more to beneficence and technical feasibility than meets the eye**

In this section, I will show that technical feasibility and beneficence of research as reasons in favour of extending the limit of embryo research are not as fundamental as those who advocate this change in the law claim. Accordingly, I scrutinise the arguments in favour of the extension of the 14-day limit, while I leave unchallenged those presented by the advocates of a more restrictive regulatory framework for embryo research. The rationale behind this choice does not rest on my own view on embryo research, as I do not necessarily share the beliefs and values of those against this practice. However, it is often argued by proponents of technological changes that the burden of justifying one's own claims rests solely on those who take a precautionary approach to technological progress [46–48]. Against this view, I propose that both those in favour and against embryo research ought to share the burden of justifying their moral views.

### **Facts, values and rationality**

Technical feasibility as a reason in favour of extending the limit relies (i.e. practice *x* is now technically feasible, so there are good reasons to change the rule) on the premise “practice *x* is technically feasible” to infer the conclusion “there are good reasons to change the rule”. However, appealing to the beneficence of research and to its technical feasibility is more problematic than those in favour of extending the limit for embryo research suggest it is. This line of arguing is problematic because it relies on what eighteenth-century philosopher David Hume considered an “inconceivable deduction” of what *ought* to be done from a set of *is*-premises [28]. Hume believed that it was logically fallacious to infer a normative judgment (ought-conclusion) from a set of factual claims (is-premises). Thus, following Hume, the normative conclusion “there are good reasons to change the 14-day rule” cannot be rightly inferred from the factual premise “embryos can now survive in vitro for longer than before” (i.e. technical feasibility of extending the time span for embryo research). This critique of inferring normative conclusions from factual claims is similar to the critique that philosopher George Edward Moore moved to moral naturalists (i.e. those who argue in favour of a link between moral philosophy and the natural sciences). Moore argued that anyone who infers that practice *x* is good from any

preposition about the natural properties of *x* commits the “naturalistic fallacy” [49]. According to Moore, this fallacy shows how premises about some factual or natural features of practices do not support normative conclusions about these practices. Thus, anyone who supports an extension of the 14-day limit for embryo research on the basis of the technical feasibility of this research would commit the naturalistic fallacy. According to Moore, one of the main problems of moral naturalists was that they relied on purely factual premises concerning the natural features of certain practices to infer normative conclusions concerning these practices. To counter this tendency, Moore suggested instead that normative conclusions ought to be inferred from both factual and normative premises.

The argument of the beneficence of research (i.e. embryo research should be allowed for longer than 14 days due to the benefits of such research) is also more problematic than those in favour of extending the limit suggest it is. According to this argument, the 14-day limit should be extended because of the potential benefits of such research and because these benefits outweigh the costs of embryo research [5, 13, 50, 51]. This appeal to beneficence is common in bioethics and it is often used by those who take a utilitarian stance on the ethical assessment of scientific progress, technologies and practices [3, 46, 52–54]. Proponents of what I have called the argument of the beneficence of research rely on historical evidence to support their claim: they argue that since technological and scientific progress in medicine proved to be beneficial to humankind, it should be allowed to continue. Returning to embryo research, those who appeal to the beneficence of research to extend the 14-day limit ground their argument on the past benefits that embryo research brought about, and on the potential benefits that the extension of the limit could bring about [4, 5].

At first sight, it seems fairly obvious that if something is beneficial, even only potentially beneficial, it should be allowed. However, this approach is problematic for a number of reasons and scholars have criticised bioethicists, institutions and scientists for their often-hyped claims concerning the benefits of new technical possibilities [55–58]. Firstly, the argument of beneficence and its proponents rely on an optimistic view of scientific progress, research and technologies [55, 59, 60], a view that echoes the post-illuminist positivistic ideas of science and technology, and that often overemphasises the potential benefits of scientific research [56, 58, 59] and its understating as a progressive and linear endeavour [61, 62]. Secondly, the argument is problematic because it relies on a misleading estimation of costs and benefits. The benefits taken into consideration for the cost-benefit assessment are not the benefits of embryo research for the embryos, as embryo research does not

benefit embryos. Instead, the benefits considered are those to society, to existing and future individuals. On the contrary, the costs taken into account for the cost-benefit assessment are not those to society, but to the embryos used for research. Those who emphasise benefits of embryo research over its costs do not grant moral status to the embryos, nor do they believe that embryos are capable of experiencing pain (i.e. being harmed). Hence, they do not really see any cost associated with embryo research, and they thus conclude that benefits outweigh these (inexistent) costs. The substantial disagreement over the moral status of the embryos and the criticism moved against research on human embryos show that embryo research is a controversial and not-settled issue [15, 63]. For this reason, the costs of extending the limit beyond the 14th day, and of embryo research more generally, might be higher than proponents of embryo research like to admit. Embryo research has a societal cost of offending certain moral feelings on the value of early human life, and not respecting certain strongly held convictions on how we ought to treat human embryos. Thus, individuals who hold such views may find themselves feeling alienated from or devalued by society [17, 18, 64]. Possibly, proponents of embryo research who argue from a utilitarian standpoint, and who rely on the argument of the beneficence of such research, are aware of the possibility of offending moral feelings and strongly held beliefs, but they still consider the benefits of embryo research greater than the costs of offending the people who hold these feelings.

One of the reasons why many proponents of embryo research do not grant moral worth to these feelings, and to the opponents’ arguments, is that they consider their views to be fundamentally flawed, irrational and not grounded in scientific evidence. Most advocates of embryo research thus dismiss the view that embryos are (future) persons and that embryo research would violate these future persons’ dignity on the grounds of the irrationality of such ontological claims. For to them, these claims are based on faith rather than reason and factual considerations. However, it is important to note that those in favour of embryo research who argue from supposedly rational positions do not live up to the very same standards of rationality that they require of their opponents. In this sense, dismissing questions related to human dignity and the moral status of the embryos on the basis of their irrationality and lack of scientific support, becomes problematic [65, 66]. Scientific evidence is often interpreted according to one’s own pre-existing moral convictions, so-called evidence-based claims are still influenced by these moral convictions and by the way bioethicists react and argue about new technical possibilities [56, 67, 68]. Thus, irrational beliefs are not an exclusive ownership of those arguing against embryo research: similar irrational beliefs



play a role in assessments of embryo research put forward by those in favour of embryo research on the grounds that it can save future lives.<sup>10</sup>

### Slippery slope

The slippery slope argument offers a last reason of caution against embryo research [69–71]. The slippery slope argument entails that allowing practice *x* (in this instance, allowing embryo research or extending the limit for embryo research) would initiate a process leading to unethical practices *w*, *y*, *z*. The slippery slope argument against embryo research is approximately like this: embryo research should not be allowed/the limit should not be extended because allowing research on embryos in a very early stage of their development/extending the limit beyond day 14 will lead to the permissibility of research on fetuses and new-borns. The argument voices the concern that once we become accustomed to research on pre-embryos, we will extend the permission for research on embryos on a later stage of development; once we become accustomed to this too, then we will allow research on fetuses and babies. ‘Slippery slopers’ believe that morally problematic practices such as embryo research should not be allowed, or the limit should not be extended, because of the difficulties of drawing a line between practices currently considered less morally problematic, such as research on pre-embryos, and practices currently considered highly immoral, such as research on fetuses at a late stage of their development. These arguments are widely criticised in the philosophical arena for their lack of empirical evidence, and for not considering that government regulations can be used to prevent such scenarios from coming into being [72–74]. In spite of these critiques, they are still used in debates on technological advances, scientific research and policy making [68, 69, 71, 75]. The persistence of slippery slope arguments in academic works and policy making seems to suggest that attempts from philosophers to discredit this argument have been unsuccessful. The charge of starting a slippery slope towards inadmissible practices is still a powerful one [63, 68]. An analysis of the theoretical fallacies and merits of this argument is beyond the scope of the paper, as is a final assessment of its validity. However, it is important to note that extending the limit beyond the 14th day of development will provide support to those who rely on the slippery slope argument to oppose embryo research. This might have non-negligible social consequences. For example, extension of the limit for embryo research would show that what is feared by ‘slippery slopers’ (i.e. that once a practice becomes legal it is difficult to prevent the permission of its future developments) can eventually become a reality.

Even if the limit was extended only for a few days, ‘slippery slopers’ might take this extension as a sign that their fears are well grounded, contrary to what their critics argue.

### Is compromise the best way forward?

Let me take stock of what I have said thus far. In the previous section, I have shown how the arguments of beneficence and technical feasibility in favour of embryo research and of extending the 14-day limit are less straightforward than their proponents seem to suggest. I have also suggested, using the slippery slope argument as an example, that extending the limit for embryo research might undermine public trust in scientists, regulators and overseeing bodies. In order to show the importance of compromise and the value of respecting pluralism in the context of embryo research, I will not juxtapose the arguments of the beneficence of research and of technical feasibility with arguments pertaining to the sanctity of human life and human dignity. These arguments arise in the context of fundamental disagreements concerning the beginning of human life, the value of personhood, and concerning what respect human dignity ought to entail. They are portrayed as factual questions by both advocates and critics of research (i.e. research beyond the 14-day should not be allowed/should be allowed because human embryos *are/are not persons* and doing research on them would/would not violate their dignity); however, they are not merely a matter of fact, but they are informed and shaped by values, feelings and beliefs. Regardless of one’s opinion regarding the values and beliefs of those defending the sanctity of life view, the burden of justifying one’s claim should rest both on those defending this view and on those advocating technological progress, contrary to what seems to be normally believed [48].

What I intend to argue in this last section is that even if the question of the moral status of the embryos cannot be easily settled, there are two arguments in favour of reaching a compromise and respecting value pluralism in the context of embryo research: the argument of trust and the argument of respect. I argue that the argument of trust in favour of compromise, albeit being sound and widely used, could, in certain instances, assume instrumental and paternalistic forms. I then argue that in the context of embryo research and more generally in the governance of scientific and technical breakthroughs it would be helpful to employ what I call the argument of respect.

### The argument of trust and the argument of respect

The first argument in favour of reaching a compromise that, other things being equal, respects value pluralism is what I define as “the argument of trust”. It is structured as follows:

- a) Scientific research is important because it improves people's lives and it should be allowed to carry on
- b) Public trust is necessary to carry on scientific research
- c) Therefore, public trust in scientific research ought to be preserved

Given competing views concerning the moral status of the embryo, this argument provides a reason in favour of finding a solution of compromise that accommodates as much as possible these views and avoids the risk of overriding those of one camp with those of the other. The argument of trust relies on premise a) to show that people's lives are improved by scientific research [76]. It relies on premise b) to show that public trust is a necessary condition for scientific research to be carried on [77, 78]. Trust is needed to ensure public acceptance of concrete applications of research; to preserve public confidence in policies informed by scientific research; and to allow the investment of public resources in scientific research [77, 78]. In the context of embryo research, the argument shows that, given the potential benefits of embryo research (premise a), and given the importance of public trust to carry on this type of research (premise b); there are good reasons to preserve public trust (conclusion c). Following this argument, it is possible to draw two conclusions: on the one hand, if the extension of the 14-day limit for embryo research is strongly opposed by the public,<sup>11</sup> then there are good reasons not to extend the limit. On the other, if opposing views coexist in the public understanding of embryo research, then there are good reasons to find a solution that strikes a compromise between these views.

The 14-day limit was a solution of compromise between conflicting moral views designed to maintain public trust whilst allowing research to go forward [12, 24, 79]. Today, there are two questions that need to be addressed, an empirical and a normative-theoretical question. The empirical question is whether the public (or at least a vast majority of it) is against the extension of the 14-day limit for embryo research. The normative-theoretical question is whether public opinion should influence the decision to change or retain the current 14-day rule, and if so, to what extent. An implication of taking into account the empirical question is that, if the public view of embryo research has become more favourable, then there is at least one good reason in favour of revisiting the 14-day rule.<sup>12</sup> In January 2017, a YouGov poll commissioned by the BBC in the United Kingdom, asked respondents' views on an extension of the limit up to the 28th day. Interestingly, 48% of the 1740 respondents said that they would be in favour of extending the limit, while 19% wanted to keep the current limit. In addition to these respondents, 10% maintained that they would want embryo research to be banned altogether, while 23% did not express any of the

aforementioned preferences [80]. In addition to the empirical question regarding public attitudes towards the extension of the 14-day limit, one may wonder how such attitudes would be towards therapies and scientific results obtained thanks to research on embryos beyond this limit in countries that may extend it. Currently, the 14-day limit is either enshrined in the laws (for instance in the United Kingdom, Canada and Spain) or specified in the scientific guidelines (for instance in Singapore, China and in the United States) of many countries. However, these regulatory frameworks may change in the future. Hence, if this becomes the case, it would be interesting to investigate public attitudes towards those therapies and other advances of basic research that are made possible by research in countries that allow embryo research beyond day 14.<sup>13</sup>

I will not provide an answer to these empirical questions here, if only because of the dearth of empirical data on public attitudes towards the extension of the limit, and embryo research more generally. Regarding, instead, the normative-theoretical question (i.e. whether public opinion should influence the decision to change or retain the current 14-day rule) the argument of trust would indicate that the answer is yes: public opposition to extending the 14-day rule should prevent its extension, while public agreement to a proposed change (i.e. the 28-day limit or other future proposals) should facilitate its extension. The risk of proceeding regardless of public attitudes towards an extension of the limit is that policies derived by embryo research will not be backed up by public consensus and applications of embryo research (e.g. therapies developed thanks to the knowledge yield by embryo research) not accepted. If the importance of maintaining public trust in scientific research (premise b) is motivated by these considerations, *then* it seems that public trust is only valued for instrumental and extrinsic reasons. In other words, this understanding of the importance of maintaining public trust in scientific research does not value public trust for its own sake, but only for its role in allowing research to go forward. What is problematic of this approach to public trust is that it offers a consequentialist reason in favour of respecting value pluralism, a reason that pertains to the better tangible outcomes of respecting value pluralism over other strategies of governance. In addition to this, when the instrumental justification of maintaining public trust is associated with a representation of the public as ill-informed and with little or no understanding of the potential benefits of research, it could be motivated by paternalistic considerations. Scientists and ethicists may risk misinterpreting public concerns and views over embryo research as the result of a lack of



expertise or evidence-based information rather than a matter of legitimate and genuine disagreement over values [81, 82].

The second premise of the argument of trust, however, could be also motivated by a concern for a deliberative conception of democracy. This conception of democratic governance requires to both citizens and their representatives to provide public justifications of their views and to engage in deliberative processes. Public trust becomes then fundamental to allow these deliberative processes to take place and to foster better strategies for policy-making [82, 83]. These deliberative processes of mutual exchange between experts and the public, together with a commitment to respecting conflicting moral views (i.e. respect for value pluralism) provide a reason in favour of finding a solution of compromise that, given competing views concerning the moral status of the embryo, respect this plurality of views and values regarding embryo research. These considerations concerning the importance of maintaining public trust echo other considerations employed to defend democracy as a political system and as a valuable form of governance. These include, for instance, equality: given the existence of conflicting views, values and beliefs, a good reason to respect them is that people or groups holding these different views will be respected by being granted an equal say on matters of common concern [84, 85]. Mertens and Pennings [8] have argued in favour of the benefit of compromise in the context of different policies regulating embryonic stem cell research and have concluded that there is a moral obligation to respect conflicting moral views [8]. Similarly, Devolder argued that in spite of the epistemic costs of compromise, middle-ground positions could still be defended in the context of policy-making [6]. What I suggest here is that the commitment to a democratic decision-making process entails a fundamental respect for value pluralism [86]. In Warnock's and the IVF-Inquiry's time, this respect for value pluralism translated into a deliberation resulting in the 14-day rule. Today it translates into favouring an assessment of the rule and of the potential reasons to change it that once again takes into account the conflicting moral views held in society; an assessment that cannot rest on the argument of the beneficence of research and of scientific feasibility alone.

## Conclusions

In this article, I have argued that the 14-day limit for embryo research is not valuable *in spite of* being a solution of compromise, but rather *because of* it. The idea of a democratic society is that even those who

do not accord intrinsic value to the human embryo should respect value pluralism and accord moral worth to opposing views. For this reason, any proposal to change the 14-day rule needs careful evaluation of the scientific feasibility and effective benefits of embryo research; it needs an extensive inquiry into public attitudes concerning embryos; and it needs a deliberative process that takes these elements into account. It does not need positions that consider only the beneficence of research and its technical feasibility. This would be undemocratic and potentially a move not backed up by a rigorous assessment of the science behind embryo research. Warnock and the other members of the IVF-Inquiry, albeit possibly guided by utilitarian-inspired views, opted for valuing a solution of compromise over other solutions [87, 88]. They did so behind closed doors. In this sense, the recent experiments published in *Nature* and *Nature Cell Biology* and the newly sparked debate on embryo research represent a valuable opportunity to begin a truly deliberative and democratic debate on this issue [82, 86]. All in all, greater technical potential translates into greater responsibilities and need for deliberation.

## Endnotes

<sup>1</sup>These embryos are not implanted in utero but frozen for further implantation. When a successful pregnancy is established, it had to be decided what do with these supernumerary frozen embryos.

<sup>2</sup>For a detailed analysis of this alternative and of its limits, see the work of Katrien Devolder [6].

<sup>3</sup>It must be noted that these two alternatives have been criticised for a number of reasons. For instance, it is unclear whether parthenotes are significantly different from human embryos and whether ANT really escapes the ethical challenges of embryo research and whether it is a scientifically realistic alternative [6].

<sup>4</sup>The submissions from the experts can be found at the House of Commons Library, but they have never been published.

<sup>5</sup>I commented elsewhere that this line of argument is problematic [61].

<sup>6</sup>I am grateful to one of the reviewers for raising this point.

<sup>7</sup>In the United Kingdom, the law regulating MRTs allows both female and male embryos to be transferred in utero. This is different from the American approach to the clinical implementation of these novel techniques: the National Academies for Science, Engineering and Medicine (NASEM) Report recommended that only male embryos should be implanted in utero [35, 89].

<sup>8</sup>For insightful analyses of the MRTs debate and of the ethics of these techniques, see [41–43, 90, 91].

<sup>9</sup>The Nuffield Council on Bioethics is an UK-based independent institution that examines ethical issues arising in the field of biotechnology and biomedicine.

<sup>10</sup>For a detailed discussion of such position in another context (i.e. the debate on human enhancement), see [48].

<sup>11</sup>It must be noted that the idea that 'the public' is against scientific developments and breakthroughs is criticised for being artificially constructed (see for instance [58]).

<sup>12</sup>Other good reasons include technical feasibility, public utility and so forth.

<sup>13</sup>A case in point is Germany, which allows research on embryonic stem cells that are produced abroad (i.e. in countries with less restrictive legislations) before January 2002 (when the German Stem Cell Law was issued), but does not allow to derivation of stem cells from super-numerary embryos [6].

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## 6 Appendix 6

Cavaliere, G., Devolder, K., & Giubilini, A. (2019). Regulating genome editing: For an enlightened democratic governance. *Cambridge Quarterly of Healthcare Ethics*, 28(1), 76-88.

## Articles

# Regulating Genome Editing: For an Enlightened Democratic Governance

GIULIA CAVALIERE, KATRIEN DEVOLDER, and ALBERTO GIUBILINI

**Abstract:** How should we regulate genome editing in the face of persistent substantive disagreement about the moral status of this technology and its applications? In this paper, we aim to contribute to resolving this question. We first present two diametrically opposed possible approaches to the regulation of genome editing. A first approach, which we refer to as “elitist,” is inspired by Joshua Greene’s work in moral psychology. It aims to derive at an abstract theoretical level what preferences people would have if they were committed to implementing public policies regulating genome editing in a context of ethical pluralism. The second approach, which we refer to as the democratic approach, defended by Francoise Baylis and Sheila Jasanoff et al., emphasizes the importance of including the public’s expressed attitudes in the regulation of genome editing. After pointing out a serious shortcoming with each of these approaches, we propose our own favored approach—the “enlightened democracy” approach—which attempts to combine the strengths of the elitist and democratic approaches while avoiding their weaknesses.

**Keywords:** genome editing; public engagement; public policy; democracy; moral psychology; moral pluralism

With every significant scientific breakthrough that could have significant societal impacts, such as the development of a new biotechnology, ethical questions typically arise at two levels. At the first level, there are *substantive ethical* questions, such as questions regarding the moral status of the new biotechnology and the ethical dilemmas that may arise from its application. Questions at the second level pertain to how we should regulate this biotechnology and who should decide about how to regulate it. We will refer to these as *ethical-political questions*.

Within society and among bioethicists, there is often significant disagreement at the level of substantive ethical questions, which is not surprising given that our views are influenced by highly diverse political, cultural, moral, and religious beliefs. Persistent disagreement at this level is not necessarily problematic. The coexistence of fundamentally different ethical views is not only inherent to democratic societies<sup>1</sup>; it is often considered essential for them to thrive.<sup>2</sup> Arguably more problematic is disagreement at the level of ethical-political questions, as this could hinder the policy-making process and leave controversial biotechnologies unregulated, or regulated in a problematic way, e.g., in a way that alienates a large section of society.<sup>3</sup> This is, arguably, what happened with the regulation of genetically modified (GM) foods.<sup>4</sup> Governments and scientists have been criticized for not taking the public’s concerns about GM foods sufficiently seriously and for misidentifying the nature of their concerns, which then contributed to a lack of public support for the development of this technology, and to a general mistrust in science.<sup>5</sup>

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The recent debate on genome editing raises concerns previously discussed in the debates on GM foods and rDNA experimentation,<sup>6</sup> as well as new questions arising from the efficacy, precision, and relatively low cost of application of genome editing.<sup>7</sup> The possibility of inserting heritable changes in human embryos has attracted the most attention. Some argue that genome editing in human embryos should be pursued, as it could prevent particular genetic diseases from being passed on from one generation to the next.<sup>8</sup> Others warn that it will be too difficult to (ever) assess the technology's safety, and that, therefore, we should probably not pursue it.<sup>9</sup> In addition, manipulating human genes more generally has been criticized on the ground that it will erode the intrinsic value of what is naturally produced,<sup>10</sup> will be tantamount to "playing God,"<sup>11</sup> or will result in the resurgence of eugenics.<sup>12</sup>

The debate on genome editing has so far primarily focused on ethical questions at the substantive ethical level, that is, questions about the moral status of genome editing and, especially, its application in human embryos. Limited attention has been devoted to questions regarding its regulation.<sup>13</sup> This limited attention is problematic, given the pressing need to regulate genome editing technologies and the potential negative societal impact of regulations that alienate large swaths of society.

Because the debate on genome editing is just emerging, there is an opportunity to approach it with fresh eyes and to shape it in a way that includes discussions of ethical-political questions. In our view, such inclusion would ensure that regulations on genome editing take societal views into account, something which, as we will argue, is of the utmost importance if we want to implement ethically acceptable policies. Discussions of ethical-political questions regarding genome editing can also inform wider debates on the regulation of science in democratic societies characterized by a plurality of coexisting views. As Sheila Jasanoff et al. have pointed out, genome editing raises "basic questions about the rightful place of science in governing the future in democratic societies,"<sup>14</sup> and as Francoise Baylis has suggested, genome editing offers an opportunity to rethink existing mechanisms of public engagement and to identify the "common interests that might rightfully guide policy deliberations."<sup>15</sup>

We take on the challenges that Baylis and Jasanoff et al. identify by exploring possible approaches to regulating genome editing that lie at the opposite ends of what we might call "the spectrum of public involvement in policy making." We first sketch an approach that does not take into account the *actual* preferences of those potentially affected by genome editing and its regulation, but rather aims to derive at an abstract theoretical level what preferences people would have if they were committed to implementing public policies in a context of ethical pluralism; this is a strategy proposed by Joshua Greene. After pointing out a serious shortcoming of this approach, which we dub "elitist," we present a diametrically opposed approach, as defended by Baylis and Jasanoff et al. We refer to this approach as "democratic," as it emphasizes the importance of including the public's expressed attitudes in the regulation of genome editing. We conclude that this approach also has a serious shortcoming and propose our own favored approach, the "enlightened democracy approach," which attempts to combine the strengths of the elitist and democratic approaches without their weaknesses. Our approach is inspired by the literature on deliberative democracy.<sup>16</sup> It relies on a democratic process as well as on expertise to identify people's preferences and to develop policies that reflect them.

### The Elitist Approach

Ideally, *since we live in democratic societies and we value democracy*, genome editing should be regulated in a way that all people *can* agree upon. However, universal or even very widespread agreement is unlikely to occur, given that views at the level of substantive ethical questions tend to influence those at the level of ethical-political questions. Typically, those who think it is morally desirable, or even morally obligatory, to pursue genome editing will favor permissive regulations,<sup>17</sup> whereas those objecting to applications of the technology, or to the technology itself, will favor more restrictive regulations<sup>18</sup>

How then are we to make progress at the level of ethical-political questions?

One approach we could adopt is to leave aside the expressed views on the regulation of genome editing and determine what people *would* agree upon *under ideal conditions*.<sup>19</sup> What these ideal conditions are is of course up for debate, but throughout history, many philosophers have focused on the relevance of reason, or rationality, to the resolution of ethical questions.

For example, Baruch Spinoza wrote that “men who are governed by reason—that is, who seek what is useful to them in accordance with reason, desire for themselves nothing, which they do not also desire for the rest of mankind, and, consequently, are just, faithful, and honorable in their conduct.”<sup>20</sup> The idea is that people “governed by reason” will agree upon universal norms that would apply to themselves as well as to others. Unfortunately, moral philosophers who have tried to ground their proposed ethical theories on the basis of reason alone have failed to reach an agreement on what reason requires or on what the rational—and therefore the ethical—way to regulate human behavior is. Indeed, the two main normative ethical theories that both claim to be grounded in rationality—Kantianism and utilitarianism—are often taken to lie at opposite ends of a spectrum, one grounding a strictly deontological approach and one grounding a strictly consequentialist one. How, then, could we rely on reason or rationality to determine how we should regulate genome editing? We could turn to political philosophers, but it seems like the best we can do then is to agree to disagree and to accept disagreement among reasonable ethical views within a framework of political liberalism.<sup>21</sup> However, what liberal policies should admit as a reasonable view turns out to be difficult to establish, in particular when the disagreement is so deep that it involves not only substantive ethical views but also ethical-political views. What kind of principles can reasonably settle a disagreement about how to regulate a technology whose moral status is the subject of substantive ethical disagreement? The answer remains unclear.

Perhaps we could turn to moral psychology for help. Recent work in moral psychology, particularly with regard to the interplay between reason and moral intuitions and emotions in our moral and political judgments,<sup>22</sup> could potentially support ethical theories grounded in reason or rationality. In other words, an understanding of how moral judgments are formed could perhaps inform an account of how rationality could allow us to find some form of agreement at the ethical political level in the face of persisting and unresolvable disagreement at the substantive ethical level. In the remainder of this section, we focus primarily on how the work of Greene in moral psychology could underpin an approach that seeks to determine what regulations on genome editing people would agree upon if they were governed by reason. We do appreciate that Greene’s work is debated

on methodological and normative grounds,<sup>23</sup> and we do not commit ourselves to his particular approach to the formation of moral judgments. What we are offering here is merely one possible heuristic that could underpin the “elitist” approach, and what we say is compatible with rejecting some specifics of Greene’s model.

On the basis of magnetic resonance imaging (MRI) studies and psychological experiments involving people’s responses to variations of the so-called trolley problem,<sup>24</sup> Greene has developed a dual-process model of how people’s moral judgments are formed.<sup>25</sup> On Greene’s model, there are two modes of making (moral) judgments: an automatic and a manual mode (what Daniel Kahneman would call “thinking fast” and “thinking slow”). In everyday situations, we normally make moral judgments in automatic mode, that is, on the basis of intuitive and emotive responses (such as the judgment that it is wrong to push a man onto the track so that he would stop a trolley and prevent five people from being killed). Such automatic mode is the result of how morality evolved to facilitate cooperation with other members of the small groups, or “tribes,” within which individuals used to live. Responding to ethical dilemmas in automatic mode has resulted in different “tribes,” or different moral communities, developing different intuitive and emotive responses (e.g., more conservative, or more liberal) to ethical dilemmas.<sup>26</sup> This automatic mode coexists with the manual mode, which is guided by more reasoned reflections that can obtain once people set aside their intuitive and emotive responses.<sup>27</sup> According to Greene, the manual mode is what one could and should rely upon when it comes to solving moral conflicts arising between different moral communities. Such conflicts arise frequently today because of the globalized world in which we live, which often requires individuals belonging to different moral communities to find common solutions to ethical problems arising from the application and regulation of new technologies. Genome editing might well be one example.

Greene is convinced that if we could set aside our intuitive and automatic responses to the ethical questions that divide us, and reflect on these questions with the aid of our reflective cognitive capacities (the manual mode), we would be able to formulate a “metamorality,” that is, a “shared moral standard”<sup>28</sup> that is genuinely based on reason.<sup>29</sup> The metamorality would be a “global moral philosophy that can adjudicate among competing interests of its members” and that would allow “trade-offs among competing tribal values.”<sup>30</sup> In order to make these trade-offs, however, we need a common currency of value that all human beings can acknowledge, even if it conflicts with some of the views developed in automatic mode.<sup>31</sup> Thus, even if some people disagree on the shared moral standard identified (due to their automatic moral mode), everyone should be able to *understand* (due to their manual moral mode)<sup>32</sup> this standard and its relevance for approaching ethical disputes. So, how to find this shared moral standard?

According to Greene, adopting the manual mode and favoring reasoned reflection instead of automatic intuitive responses to ethical questions allows us to appreciate that there are two essential aspects of a genuinely ethical approach. The first is the value of impartiality—the idea that, from the point of view of the universe (so to speak), each person is as important as any other. Greene acknowledges that none of us are really truly impartial, but notes that we can all acknowledge the importance of impartiality as a moral ideal.<sup>33</sup> The second aspect of a genuinely ethical approach is the recognition of the value of happiness, which matters to everyone.<sup>34</sup> Recognizing that happiness is what ultimately matters and



that, from the point of view of the universe, no one matters more than anyone else, lies at the core of utilitarianism, which Greene proposes to rename “deep pragmatism.” This is to emphasize that it is the approach that is most likely to work in resolving moral conflicts because it is the one on which people from different moral tribes could get to agree upon once they switch from the automatic to the manual mode of reasoning.

So, how could an approach based on Greene’s ideas about how to resolve moral disagreement in a globalized world help us regulate genome editing? Policies would need to be developed using the utilitarian standard. In other words, alternative regulatory strategies would need to be evaluated on the basis of their capacity to generate the greatest happiness for the greatest number, as the famous utilitarian slogan goes. However, whether different types of policies to regulate genome editing can be expected to maximize happiness is a question that is not easily settled. Different sorts of experts, including for instance legal experts, policy-makers, scientists, ethicists, and sociologists could contribute to the assessment of the expected consequences of potential regulatory strategies, of what “happiness” could mean, and of how the consequences could contribute to the promotion of happiness. (Within this framework, a relevant and philosophically interesting question that would need to be addressed, but which we raise here only to leave aside, is one about the proper role of “moral experts,”<sup>35</sup> i.e., people who know well different possible moral theories and know how to weigh conflicting moral values against one another in the light of those moral theories.)<sup>36</sup> Presumably, these experts would be people who are able to switch to the manual mode and set aside automatically formed intuitions and emotions. Because the proposed approach heavily relies on some sorts of experts, we propose to refer to it as an “elitist approach.”

In principle, this approach could be the ethically optimal solution to the moral disagreement about how to regulate genome editing: it would be the solution that perfectly rational people would endorse. However, there are also some serious shortcomings with this view, which make it a problematic approach to regulating genome editing.

### A Shortcoming of the Elitist Approach

We focus our criticism on an elitist approach modeled on Greene’s proposal, but our arguments would also apply to other similarly elitist approaches.<sup>37</sup>

The most serious shortcoming is that the elitist approach is not democratic, in the sense that the decision-making process does not require the involvement and participation of all those who will be affected by the decisions taken. Why is this problematic?

Democratic decision-making procedures can be important for intrinsic reasons, for example because one values equality in political influence and sees democracy as the only system that can respect and preserve people’s freedom, equality, and equality in freedom.

But a democratic decision-making procedure can also be important for instrumental reasons, because it is essential to achieve trust and legitimacy, which both have desirable consequences for society.<sup>38</sup> Relying on an elitist approach to regulate genome editing excludes large segments of the population from the decision-making process. Expertise can often be “exclusionary and restricted,” as it represents

“the command of knowledge within a defined domain by some persons that is not commanded by others.”<sup>39</sup> As a result, those excluded may lose trust in the policies resulting from the elitist approach and in the various experts that have contributed to them. Loss of trust in experts may have a wide societal impact. Moreover, when legitimacy<sup>40</sup> obtains, people are more inclined to conform to the policies and to avoid forgoing the potential benefits the technology in question may bring about. As is often highlighted in the literature on trust and expertise, it would be difficult for science to make progress without this trust<sup>41</sup> and without legitimacy.<sup>42</sup> In addition, it has been argued that relying on a democratic process is good because involving rival points of view is more likely to lead to better policy outcomes, given that different ethical and practical problems are more likely to be considered and analyzed.<sup>43</sup>

These reasons point to something similar: in liberal, democratic societies, public policies, and political decisions in general, cannot do without some form of support by the people who will be affected by those policies.

### **The Democratic Approach**

This importance of relying on a democratic process to regulate genome editing echoes a shared view among the few scholars that have addressed the level of ethical-political questions specifically regarding genome editing<sup>44</sup> (and indeed, some preliminary experiments of public dialogue in this direction have been carried out).<sup>45</sup> It has been argued that an absolute condition of developing policies to regulate this technology is public engagement and the inclusion of public views in policy-making processes. Institutional bodies such as the U.S. National Academy of Sciences or the U.K. Nuffield Council on Bioethics endorse this view. For instance, following the December 2015 International Summit on Genome Editing, the National Academy of Sciences Organizing Committee released a statement that called for the establishment of an “ongoing international forum to discuss potential clinical uses of gene editing.” According to the statement, this forum should be “inclusive among nations” and should

Engage a wide range of perspectives and expertise—including from biomedical scientists, social scientists, ethicists, health care providers, patients and their families, people with disabilities, policymakers, regulators, research funders, faith leaders, public interest advocates, industry representatives, and members of the general public.<sup>46</sup>

Echoing this conclusion, Baylis emphasizes the need to collectively discuss strategies for governance that are based on a “broad consensus” which, in turn, should be achieved through “broad-based participation by persons from around the world with a range of perspectives and interests.”<sup>47</sup>

An even more radical position is expressed by Jasanoff et al., who openly criticize the reliance on experts to address the regulatory challenges raised by genome editing and argue that public engagement cannot be reduced to asking questions to the public that have been preselected, preapproved and deemed appropriate by experts. They claim that

Even where there are calls for “broad public dialogue,” these are constrained by expert accounts of what is proper (and not proper) to talk about in ensuing deliberations. When larger questions arise, as they often

do, dissent is dismissed as evidence that publics just do not get the science. . . . The impulse to dismiss public views as simply ill-informed is not only itself ill-informed but is problematic because it deprives society of the freedom to decide what forms of progress are culturally and morally acceptable.”<sup>48</sup>

### A Shortcoming of the Democratic Approach

Unfortunately, the democratic solutions advocated by Baylis and Jasanoff et al. also have a serious shortcoming. If one of the problems with the elitist approach was that it sacrificed democratic values for the sake of imposed rationally inferred moral values, the problem with the democratic model is rather the opposite one: it sacrifices reasoned and well-informed decision-making for the sake of democratic values. The problem with Baylis’ proposal is that due to the fundamental moral disagreement at the level of substantive ethical questions, it is likely that a “broad based participation by persons from around the world with a range of perspectives and interests” will lead to fragmentation rather than to the widespread consensus that Baylis advocates. In addition to this, while it is true that Baylis does take into account certain conditions that need to be met in order to achieve her particular conception of consensus,<sup>49</sup> consensus may not be the most desirable aim to pursue, both because it may be a “mask hiding relations of domination and exclusion”<sup>50</sup> and because it might be reached “to the detriment of opponents or the recalcitrant who have been unable to express themselves or who have been silenced.”<sup>51</sup> The problem with the proposal of Jasanoff et al.—we contend—is instead that it challenges the very idea of expertise and with it, the idea of relying on experts. This is problematic as many people’s decisions may be uninformed or, if we may believe Greene, based on automatically formed and intuitive responses.

### The Enlightened Democracy Approach

We propose that regulations for genome editing ought to be developed on the basis of what we call an “enlightened democracy” approach, which, in our view, includes the strengths of the elitist approach and the democratic approach suggested by Baylis and Jasanoff et al., while avoiding, to the greatest extent possible, their shortcomings. The enlightened democracy approach to regulating genome editing relies partly on Greene’s ideas of a shared moral standard and the relevance of experts in policymaking, and partly on the literature on deliberative democracy.<sup>52</sup> At the same time, our proposed approach takes up the challenges raised by Baylis, and especially by Jasanoff et al., in favor of democratic deliberation and broad-based public engagement. Our proposal is enlightened, in that it aims to include the various views of different categories of experts, and democratic, in that it aims to open up the debate to various sorts of nonexperts and engage with public views on genome editing.

The first characteristic of our approach is that it rejects an agenda for genome editing that is solely based on what experts define as worth pursuing. At the same time, it grants experts an ancillary but necessary role in the development of such an agenda. Building on the work of Philip Kitcher, we argue that the policies regulating genome editing research and implementation should strive towards the ideal of “well-ordered science.” According to Kitcher, scientific research and

clinical applications are well-ordered when their agendas coincide with ideal deliberators' judgments and world views, which in turn are representative of the diversity of judgments and world views coexisting in a given community. In the context of genome editing and its applications, this ideal entails that such applications are well-ordered only if they align with what people—coming together and discussing their values and preferences—would decide in a deliberative process. The deliberations among people aim to provide “the most justifiable conception for dealing with moral disagreement in politics.”<sup>53</sup> This means that, as we saw above, even if disagreement often cannot be avoided, people's preferences should be taken into account in order to avoid distrust and illegitimacy. In addition, deliberations among peers facilitated and informed by experts allow that preferences are perfected and epistemic flaws ironed out. A deliberative process that involves ordinary people as well as experts seems to us the most desirable strategy on two desiderata, namely “the degree to which policy outcomes match the substantive goals of society in question; and the degree to which they achieve normatively justifiable ends.”<sup>54</sup>

The second characteristic of our proposed approach is that it sets certain background conditions to participating in these deliberations.<sup>55</sup> Contrary to the proposals such as those of Jasanoff et al., and also James Ben Hurlbut, people entering these deliberations should meet certain criteria in order to avoid the two dangers outlined above (i.e., regulations that do not match societal goals and that do not achieve normatively justifiable ends). Deliberators need to meet “epistemic conditions”<sup>56</sup> of mutual engagement, which require deliberators to not rely on false beliefs about the world, to be aware of the consequences of the debated matter for one another, and to know preferences and wishes of other deliberators. With respect to genome editing, this means that deliberators should gain a basic knowledge of the functioning, potential uses, potential risks, and potential benefits of genome editing. Scientific experts, as well as social and technology studies experts, sociologists, philosophers, and lawyers would assist in bringing to light expected consequences of permissive or restrictive regulations for genome editing and make sure that deliberators can fulfil such epistemic conditions.

Other conditions for deliberators to take part in these discussions are “affective”<sup>57</sup> in that deliberators will be required to work towards the “expansion of one's sympathies, in which the perceived desires of those with whom one deliberates are given equal weight with one's own.”<sup>58</sup> These affective conditions of mutual engagement reflect also deliberative democracy's background conditions of mutual respect.<sup>59</sup> Only if both conditions apply is the process one of genuinely mutual engagement.

Moreover, epistemic and affective conditions allow for the emergence and especially the discussion of “tutored” as opposed to “raw” preferences.<sup>60</sup> There is significant disagreement among experts about substantive ethical questions regarding genome editing. These differences are likely to be equally found in wider society, where a plurality of values obtain.<sup>61</sup> Hence, deliberators may have different preferences with respect to regulations, and their judgments may be influenced by these preferences when they come together and discuss different possible routes for scientific research and applications. The preferences that these individuals discuss should, however, not be “raw” preferences influenced by whatever inclination or temporary impulse these individuals are subjected to; in other words, the preferences should not be devoid of any background

information, but rather “tutored preferences”: preferences informed by the current state of the art of the matter and especially by the significance that potential applications of the technology in question may have for people’s lives.<sup>62</sup> In addition to this, these preferences should be tutored in the sense that they will be perfected in a discussion with experts and in a discussion with epistemic peers (e.g., other members of the public participating in the deliberative processes).

In our view, these characteristics enable a deliberative process to take place, one that avoids what in our view are the most problematic shortcomings of the elitist and democratic approaches to regulating genome editing. The enlightened democracy approach could be criticized on practical and ethical grounds too, but we contend that its shortcomings should be factored against the benefits and the shortcomings of the alternatives thus far proposed. From a practical point of view, our proposed approach may still generate or fail to solve disagreement. Disagreement at the first level (the substantive-ethical) and disagreement at the second level (the ethical-political) are interlinked and mutually influenced. However, even if there is lingering disagreement, our approach will reduce the risk of stifling policy-making processes, as at least epistemic flaws will have been mitigated and the different moral beliefs and preferences discussed. As argued by Philip Kitcher,<sup>63</sup> Amy Gutmann and Dennis Thompson,<sup>64</sup> Joshua Cohen,<sup>65</sup> and— from a different perspective— Jonathan Haidt,<sup>66</sup> the give-and-take of preferences and judgments allows for addressing misapprehensions and for appreciating the value of moral beliefs different from our own. In the best-case scenario, recognizing the value of other points of view will help deliberators to engage with these points of view and perhaps to reflect on their own moral beliefs. This could help the activation of Greene’s manual mode and allow for a reasoned reflection to emerge. In some cases, the disagreement will not be resolved and the debate will remain polarized, but the mutual engagement would hopefully mitigate legitimacy problems and distrust. Our proposed approach will be criticized by those who would grant more “power to the people” and those who are wary of any involvement of experts as they predetermine the questions that are worth pursuing and hence limit the scope and type of questions that are discussed in these deliberations.<sup>67</sup> It will be also criticized by those who are wary of involving the public in discussions concerning new technologies and how they should be regulated. Without entering in a complicated discussion with both sides on burden of proof, we contend that our approach accommodates these competing views better than the alternatives.

## Conclusion

In this paper, we have proposed an approach to addressing ethical-political questions regarding genome editing—i.e., questions about how genome editing should be regulated in the face of deep and persistent disagreement about substantive ethical questions. We have sketched a possible elitist approach grounded in the metamorality proposal of Greene and based on the deliberation of some sort of experts, and then discussed the democratic approach proposed by Baylis and Jasanoff et al. We have argued that the approaches each have strengths but also significant shortcomings. We have then proposed a new approach—the “enlightened democracy” approach—that aims to reconcile the need for a democratic engagement involving mutual respect for competing views on the one hand and a



well-informed discussion on the other. Our proposal is meant to sketch a theoretical framework to inform the ethical debate on how to regulate genome editing. We appreciate that our proposed approach would need to be further developed and refined. Most notably, we have not addressed the question of how such an approach would translate into practice. In this sense, our paper is situated within the scholarship in moral and political philosophy that proposes approaches to regulate new technologies in pluralistic and democratic societies. We believe, however, that a study of the implementation of the enlightened democracy approach would be worth pursuing, perhaps in another paper.

## Notes

1. Gutmann A, Thompson DF. *Democracy and Disagreement*. Cambridge, MA: The Belknap Press of Harvard University Press; 1996.
2. Mill JS. *On Liberty*. London: Dent; 1979 (Original work published in 1859).
3. House of Lords, Selected Committee on Science and Technology. *Science and Society*. London: Her Majesty's Stationary Office; 2000.
4. Adam B, Berkhout F, Dyson T, Grove-White R, Marsden T, O'Riordan T, et al. *The Politics of GM Food: Risk, Science and Public Trust*. University of Sussex: ESRC Global Environmental Change Programme, Special Briefing; 1999; Wynne BE. The Times Higher Education Supplement. *Patronising Joe Public*; 1996 Apr 12; available at <https://www.timeshighereducation.com/news/patronising-joe-public/93081.article> (last accessed 6 March 2018).
5. Ibid. See also note 3, House of Lords 2000.
6. Jasanoff S, Hurlbut JB, Saha K. CRISPR democracy: Gene editing and the need for inclusive deliberation. *Issues in Science and Technology* 2015;32(1):37–49.
7. Ledford H. CRISPR, the disruptor. *Nature* 2015;522:20–4.
8. See, e.g., Cavaliere G. Genome editing and assisted reproduction: Curing embryos, society or prospective parents? *Medicine, Health Care and Philosophy* 2018;21(2):215–25; Gyngell C, Douglas T, Savulescu J. The ethics of germline gene editing. *Journal of Applied Philosophy* 2017;34(4):498–513.
9. Baylis F. Human germline, genome editing and broad societal consensus. *Nature Human Behaviour* 2017;1:1–3. Lanphier E, Urnov F, Haecker SE, Werner M, Smolenski J. Don't edit the human germ line. *Nature News* 2015;519(7544):410–1.
10. Kass LR. *Life, Liberty and the Defense of Dignity: The Challenge for Bioethics*. San Francisco: Encounter books; 2004; Sandel M. The case against perfection. *The Atlantic Monthly* 2004;293(3):51–62.
11. For an analysis of 'playing God' arguments see, for instance, Savulescu J, Brostrom N, Coady CAJ. Playing God. In: Savulescu J, Bostrom N, eds. *Human Enhancement*. Oxford, UK: Oxford University Press; 2009:155–80.
12. Some have argued that gene editing could lead back to eugenics: King D. Editing the human genome brings us one step closer to consumer eugenics. *The Guardian* 2017 Aug 4; available at <https://www.theguardian.com/commentisfree/2017/aug/04/editing-human-genome-consumer-eugenics-designer-babies> (last accessed 5 Mar 2018); Pollack R. Eugenics lurk in the shadow of CRISPR. *Science* 2015;348(6237):871.
13. With some exceptions: see note 9, Baylis 2017; see note 6; Jasanoff S, Hurlbut JB, Saha K. 2015; Baylis F. 'Broad societal consensus' on human germline editing. *Harvard Health Policy Review* 2016;15(2):19–22; Hurlbut JB. Limits of responsibility: Genome editing, Asilomar, and the politics of deliberation. *Hastings Center Report* 2015;45(5):11–4; Chan S, Arellano MM. Genome editing and international regulatory challenges: Lessons from Mexico. *Ethics, Medicine and Public Health* 2016;2(3):426–34.
14. See note 6, Jasanoff et al. 2015.
15. See note 9, Baylis 2017.
16. See, for instance, note 1, Gutmann, Thompson 1996; Cohen J. Deliberation and democratic legitimacy. In: Hamlin A, Pettit P, eds. *The Good Polity*. Oxford, UK: Blackwell; 1989:17–34; Gutmann A, Thompson D. *Why Deliberative Democracy?* Princeton, NJ: Princeton University Press; 2009; Kitcher P. *Science, Truth and Democracy*. New York: Oxford University Press; 2003; Kitcher P. *Science in a Democratic Society*. Amherst, NY: Prometheus Books; 2011.

17. See, e.g., Harris J. Why human gene editing must not be stopped. *The Guardian* 2015 Dec 2; available at <https://www.theguardian.com/science/2015/dec/02/why-human-gene-editing-must-not-be-stopped> (last accessed 6 Mar 2018) and Savulescu J, Pugh J, Douglas T, Gyngell C. The moral imperative to continue gene editing research on human embryos. *Protein & Cell* 2015;6(7):476–9.
18. See, e.g., note 9, Lanphier E et al. 2015; Collins FS. *Statement on the NIH funding of research using gene-editing technologies in human embryos*; available at <http://www.nih.gov/about-nih/who-we-are/nih-director/statements/statement-nih-funding-research-using-gene-editing-technologies-human-embryos> (last accessed 6 Mar 2018); and UNESCO International Bioethics Committee. *UNESCO panel of experts calls for ban on “editing” of human DNA to avoid unethical tampering with hereditary traits*; available at <http://en.unesco.org/news/unesco-panel-experts-calls-ban-editing-human-dna-avoid-unethical-tampering-hereditary-traits> (last accessed 6 March 2018).
19. Often, moral disagreement persists even in ideal conditions, among people that are well-informed and fully rational. This is what Doris and Plakias (2008) refer to as “fundamental disagreement,” which obtains even when ideal conditions are met. See Doris JM, Plakias A. How to argue about disagreement: Evaluative diversity and moral realism. In: Sinnott-Armstrong W, ed. *Moral Psychology, Volume 2: The Cognitive Science of Morality: Intuition and Diversity*. Cambridge, MA: The MIT Press; 2008:303–31.
20. Spinoza, *Ethics*, 1677 book IV, prop. XVII.
21. Rawls J. *Political Liberalism*. New York: Columbia University Press; 1993.
22. Greene J. *Moral Tribes*. London: Atlantic Books; 2014; Haidt J. *The Righteous Mind: Why Good People are Divided by Politics and Religion*. New York: Pantheon; 2012. See also: Haidt J, Bjorklund F. Social intuitionists answer six questions about moral psychology. In: Sinnott-Armstrong W, ed. *Moral Psychology, Volume 2: The Cognitive Science of Morality: Intuition and Diversity*, Cambridge, MA: The MIT Press; 2008:181–217.
23. See, for instance, Kahane G, Shackel N. Methodological issues in the neuroscience of moral judgement. *Mind & Language* 2010;25(5):561–582; Nagel T. You can’t learn about morality from brain scans: The problem with moral psychology. *The New Republic* 2013 Nov 2; available at <https://newrepublic.com/article/115279/joshua-greenes-moral-tribes-reviewed-thomas-nagel> (last accessed 6 March 2018); Wright R. Why can’t we all just get along? The uncertain biological basis of morality. *The Atlantic* 2013 Nov; available at <https://www.theatlantic.com/magazine/archive/2013/11/why-we-fightand-can-we-stop/309525/> (last accessed 6 Mar 2018).
24. Foot P. The problem of abortion and the doctrine of double effect. *Oxford Review* 1967;5:5–15; Thomson JJ. Killing, letting die, and the trolley problem. *The Monist* 1976;59(2):204–17; Thomson JJ. The trolley problem. *The Yale Law Journal* 1985;194(6):1395–415.
25. This is similar to the dual-process model that other psychologists developed with respect to the way humans make judgments more generally, see, for instance, Kahneman D. *Thinking, Fast and Slow*. New York: Farrar, Straus and Giroux; 2011.
26. See also note 22, Haidt 2012.
27. The automatic mode is activated in the trolley problem scenario in which we can save five people at the cost of killing one without having to actively push someone onto the tracks, something that many people intuitively reject.
28. See note 22, Greene 2014, at 290.
29. While the very same notion of “rationality” is itself difficult to define in philosophical terms, in psychological terms we can define practical rationality as the capacity to make decisions that are not based merely on unanalyzed intuitions and emotions. In Greene’s words, “Reasoning, as applied to decision making, involves the conscious application of decision rules. . . . Reasoning frees us from the tyranny of our immediate impulses by allowing us to serve values that are not automatically activated by what’s in front of us,” see note 22 Greene 2014 at 13.
30. See note 22, Greene 2014, at 15.
31. Ibid.
32. There is a helpful Wright (2013) analogy of metamorality as “the moral equivalent of Esperanto,” see note 23, Wright R 2013.
33. See note 22, Greene 2014, at 201.
34. This view that is shared, for instance, by Singer P. *The Expanding Circle*. New York: Farrar, Straus and Giroux; 1981 and Sidgwick H. *The Methods of Ethics*, 7th ed. London: Macmillan; 1907.
35. There is a literature, both in philosophy and within bioethics specifically, about what moral expertise is, whether it exists at all, and who counts as a moral expert, with which we do not have the space to engage here. For the purposes of our paper, however, what matters is not so much how

- moral expertise should be defined and whether it exists, but the fact that the elitist model we discuss would have to rely on some sort of moral expertise—as well as on other kinds of expertise—rather than on the active participation of the population or of some representation of it.
36. As Peter Singer says in his defense of moral expertise, “someone familiar with moral concepts and with moral arguments, who has ample time to gather information and think about it, may reasonably be expected to reach a soundly based conclusion more often than someone who is unfamiliar with moral concepts and moral arguments and has little time.” See Singer P. Moral experts. *Analysis* 1972;32(4):115–117, at 117. Similarly, Harris and Lawrence (2018) argued that “‘Ethical expertise’ if and where it exists must consist principally in the ability to create, assemble, analyze or present the combination of evidence and argument required to establish, defend, qualify, weaken or demolish a proposition of ethical significance. Or, to reveal problems or ambiguities, contradictions or inconsistencies, in short strengths and weaknesses, in ethical positions, judgments, claims or conclusions”; Harris J, Lawrence D. Ethical expertise and public policy. In: Lever A, Poama A, eds. *Routledge Handbook of Ethics and Public Policy*. Abingdon, UK: Routledge; forthcoming.
  37. For instance, these arguments would apply to elitist approaches based on the alleged moral expertise of religious authorities.
  38. See note 3, UK House of Lords 2000.
  39. Archard D. Why moral philosophers are not and should not be moral experts. *Bioethics* 2011; 25(3):119–27, at 20.
  40. Here we follow Dryzek’s (2001) definition of legitimacy, namely that “outcomes are legitimate to the extent that they receive reflective assent through participation in authentic deliberation by all those subject to the decision in question.” Dryzek J. Legitimacy and economy in deliberative democracy. *Political Theory* 2001;29(5):651–669, at 651.
  41. O’Neill O. *A Question of Trust: The BBC Reith Lectures 2002*. Cambridge, UK: Cambridge University Press; 2002; Resnik D. Scientific research and the public trust. *Science and Engineering Ethics* 2011; 17(3):399–409.
  42. See note 9, Gutmann Thompson 2009; note 13, Chan, Arellano 2016; and Parkinson J. Legitimacy problems in deliberative democracy. *Political Studies* 2003;51(1):180–96.
  43. This view was already defended by John Stuart Mill in his defense of freedom of speech of people with different moral views, see note 2 Mill 1979/1859.
  44. See note 6, Jasanoff, Hurlbut, Saha 2015; see note 9, Baylis 2017; see note 13, Baylis 2016; and Jasanoff F, Hurlbut JB. A global observatory for gene editing. *Nature* 2018;555(7697):435–7.
  45. The Royal Society—a U.K. learned society—commissioned both a public dialogue deliberative process (2013) and launched a survey (2017) on genetic technologies’ applications to plants, humans (heritable and nonheritable), nonhuman animals (pets, wild animals, and animals used as source of food). A report of the survey and of the public dialogue is available at <https://royalsociety.org/~media/policy/projects/gene-tech/genetic-technologies-public-dialogue-hvm-full-report.pdf> (last accessed 25 Apr 2018).
  46. The National Academies of Sciences Engineering Medicine. *On Human Gene Editing: International Summit Statement*; Available at <http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12032015a> (last accessed 6 Mar 2018).
  47. See note 13, Baylis 2016, at 22.
  48. See note 6, Jasanoff S, Hurlbut JB, Saha K 2015; elsewhere—and in a similar fashion—Jasanoff and Hurlbut have called for a “global observatory on gene editing” and argued that “free enquiry, the lifeblood of science, does not mean untrammelled freedom to do anything. Society’s unwritten contract with science guarantees scientific autonomy in exchange for a research enterprise that is in the service of, and calibrated to, society’s diverse conceptions of the good. As the dark histories of eugenics and abusive research on human subjects remind us, it is at our peril that we leave the human future to be adjudicated in biotechnology’s own ‘ecclesiastical courts.’” See note 44, Jasanoff, Hurlbut 2018, at 437.
  49. Baylis (2016) does not really define what she means by consensus, but she is adamant in stressing that, “consensus does not mean that everyone thinks that the decision made is necessarily the best one possible. . . . What it does mean is that in coming to that decision on one felt that her position on the matter was misunderstood or that it wasn’t given a proper hearing”; See note 6, Baylis 2016, at 22. The author also lays the condition of mutual engagement for achieve such consensus (responsibility, self-discipline, respect, cooperation, struggle).
  50. Callon M, Lascoumes P, Barthe Y. *Acting in an Uncertain World*. Cambridge, MA: MIT Press; 2001, at 4.



51. Ibid. quoting S. Jasanoff.
52. In particular, Gutmann and Thompson (1996, 2009), see note 9; Gutmann, Thompson 1996, 2009; and see note 16, Kitcher 2003, at 2011.
53. See note 16, Gutmann, Thompson 2009, at 10.
54. See note 42, Parkinson 2003, at 183.
55. See note 16, Gutmann, Thompson 2009; and Kitcher 2011.
56. See note 16, Kitcher 2011
57. Ibid.
58. Ibid., 51.
59. See note 16, Gutmann, Thompson 2009.
60. See note 16, Kitcher 2003, at 2011.
61. See note 22, Haidt 2012; Nagel T. *Mortal Questions*. Cambridge, UK: Cambridge University Press; 1979 (in particular chapter 9, The Fragmentation of Value).
62. See note 16, Kitcher 2003, at 118.
63. See note 16, Kitcher 2003, at 2011.
64. See note 1, Gutmann, Thompson 1996; see note 16, Gutmann, Thompson 2009.
65. See note 16, Cohen 1989.
66. See note 16, Kitcher 2011.
67. Hurlbut JB. *Experiments in Democracy: Human Embryo research and the Politics of Bioethics*. New York: Columbia University Press; 2017.